An exploration of the informal learning experiences of home-based car	egivers
in a non-governmental organisation in KwaZulu-Natal	

By

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Signed:		
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Name:	Dr Peter Rule	
Signature:		

# **Dedication**

This thesis is dedicated to my dearest son, Nhlanhlenhle Asante Samkele Kheswa whose existence gave me strength and courage to complete this thesis.

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### **Abstract**

Social science research on HIV and AIDS has tended to focus on the statistics regarding the spread of the pandemic and the prevention awareness campaigns. However, there has not been much research on the impact that the pandemic has on families and communities at large. Furthermore, although there are international studies very little research has been conducted on caregivers' education and training locally. Therefore, the current study was done to bridge the gap between literature and practice by conveying findings that are based on a local South African context.

The study was conducted in Mpophomeni Township, in Kwazulu-Natal. The research participants consisted of twelve home-based caregivers. The purpose of the study was to explore the informal learning experiences of home-based caregivers from a non-governmental organisation, Siyasiza, in KwaZulu-Natal. The study tried to establish what informed the informal learning experiences of caregivers. The study further investigated how the informal learning experiences were made explicit to inform further learning and also tried to find out what caregivers did with shared information to inform their practices. In order to achieve the objectives of the study a basic qualitative research design was deemed most suitable. The situated and experiential learning theories informed the study and were also used as lenses in the thematic analysis of data collected through observation, focus group discussions and in depth interviews.

The findings of the study showed that caregivers' informal learning experiences were informed by both intrinsic and extrinsic factors. The loss of own family members influenced caregivers to join the community home-based caregiving initiative to assist families affected by the pandemic. Furthermore, caregivers' informal learning experiences were driven by career-directed ambition, exemplary learning and second chance learning. The findings further indicated that, for some caregivers, once new information was obtained, it was compared with the related prior knowledge, looked at for similarities or differences, and the value added to the previous experiences was determined. The study also found that caregivers valued and appreciated the

information sharing sessions which improved their future practices and so made their jobs a bit easier.

Lastly, the study found that caregivers played a huge role in supporting the families affected by HIV and AIDS since they mediated between homes and hospital by providing basic health services.

# List of abbreviations and acronyms

**ABET**: Adult Basic Education and Training

AIDS: Acquired Immune Deficiency Syndrome

**CINDI**: Children in Distress

**CHW**: Community Health Worker

**CHBC**: Community Home-Based Care

**HBC**: Home-Based Care

**HIV**: Human Immune Virus

**ICT**: Information and Communication Technology

**NGO**: Non-Governmental Organisation

**PLWHA**: People Living With HIV and AIDS

**SA**: South Africa

**UNAIDS**: United Nation Program on HIV/ AIDS

WHO: World Health Organisation

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# **Chapter One**

### Introduction and overview

# 1.1 Focus and purpose of the study

The context of this study is a community-based NGO called Siyasiza. The organization under study operates within the boundaries of the uMngeni Municipality, which comprises 27 areas, including Mpophomeni and Howick. This NGO focusses on various activities supporting people affected by HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) in the area and works in partnership with other regional and provincial NGOs of the same purpose and the professional health sector (Hospitals and Department of Health).

Siyasiza mainly provides support for families affected or infected by the HIV and AIDS epidemic. This syndrome is spread by contact between the bodily secretions of the infected person (eg. semen or blood) and the recipient's blood through a break in the skin or mucus membranes (Webb, 1997) and spreads throughout the body weakening the whole immune system (Yerza et al, 1990).

The main aim of this NGO is to address the needs of the affected families which include poverty alleviation, medical intervention (as well as wellness promotion), psychosocial support (which involves: counselling, support-groups, bereavement work, play therapy, toy library, memory box) and sustainable micro-enterprise projects such as farming. In partnership with the governmental health sector the NGO also trains volunteers from the community in HIV and AIDS awareness, home-based care, orphan care, wellness training, basic counselling skills and spiritual support. The training initiatives resulted in some of the trainees joining the organisation (most of them as community home-based caregivers and some as counsellors) and they have identified and support families in their communities who are in need of the intervention.

Furthermore, the caregivers work all over the Mpophomeni area visiting families and orphaned children in their respective schools, offering extra care and support.

Within the Siyasiza context, there are many caregivers working with people living with HIV and AIDS (adults and children) and their families. For the purpose of this study, a caregiver is someone who provides care to a person living with HIV and AIDS (PLWHA) in the community. A primary caregiver is a community member (usually a family member) who lives with the person infected by the pandemic and provides constant care. A secondary caregiver is a caregiver (community member) who does not live in the same house as the person living with HIV and AIDS. Secondary caregivers are also called home-based caregivers since they provide home-based care and support to PLWHA and their families.

The purpose of the study was to explore the informal learning experiences of home-based caregivers from a non-governmental organisation, Siyasiza, in KwaZulu-Natal.

# 1.2 Background

The 2012 UNAIDS: World AIDS day report showed that South Africa remains the area most heavily affected by the epidemic with South Africa being the home to the world's largest population of people living with HIV (5.6 million) (UNAIDS, 2012). In provincial statistics reports on HIV and AIDS prevalence (Department of Health, 2009), it appeared that KwaZulu-Natal was the most affected province with approximately 1.7 million people (17% of the population) infected by the end of 2010. The most recent survey of pregnant women at ante-natal clinics indicates that 37.4% are infected in the province (Department of Health, 2012). However, according to the most recent reports (Department of Health, 2012) KwaZulu-Natal has recorded a notable decrease in HIV prevalence which is promising, whereas Mpumalanga has recorded an increase in the past four years which is worrisome. The Departmental reports further revealed that the HIV prevalence estimate across provinces is variable in year to year changes. "There is however a notable drop in the 2011 HIV prevalence recorded in KwaZulu-Natal with an estimate of 37.4% (95% CI: 35.8 – 39.0%). The upper limit of the 2011 confidence interval is lower than

the 2009 and 2010 estimates of 39.5% indicating a decline by 2.1% in HIV prevalence in this province" (Department of Health, 2012).

The above statistics indicate that this epidemic poses many destructive challenges for immediate family members of the affected people and the community at large (Department of Health, 2011). Furthermore, one of the destructive social impacts of HIV and AIDS is the increasing number of young parents who die and leave small children behind. Clear evidence of this is the increasing number of orphans, child headed households, other vulnerable children affected by HIV and AIDS and the inability of the extended family system to provide such children with basic needs such as shelter, food, medical care, love and support. According to the National Guideline on Home-based care and Community-based care (2001, p.2) provided by Department of Health (2009), as more people become ill, many will not be able to stay in hospitals, hospices or other institutions for care due to limited health care resources in South Africa and elsewhere.

As a result, the public hospitals send HIV and AIDS infected people home to be cared for by family members. These carers become immediate caregivers with no formal training and normally do not have sufficient resources to administer care (UNAIDS, 2008). Therefore, it is vital that government departments, non-governmental organisations (NGOs) and community forums jointly assist those affected by the epidemic in order to reduce the burden on families and local hospitals. These NGOs provide home-based care (HBC) through caregivers who visit the affected families around their communities. However, it is not easy for the NGOs to provide all the necessary services without taking into cognisance that caregivers need to be prepared for the challenges associated with HIV and AIDS issues. Caregivers as ordinary people suffer from emotional and physical strain resulting from what they experience while on duty (Akintola, 2006). Furthermore, caregivers might also fear that they might be mistrusted by the members of the infected person's family or the community at large. According to Tshabalala-Msimang (2001), insufficient empowerment of clients and caregivers regarding care/resources and diagnoses is one of the major challenges faced by HBC caregivers. Furthermore, issues that affect home-based caregivers also include their level of literacy and the training they have received for the effective performance of their tasks. Therefore, it is important that caregivers are motivated and encouraged in order to improve their literacy, which will enable them to cope with

the demands from the duties they perform. However, Turner, Catania and Gagnon (1994) argue that most of the knowledge that the caregivers have has been acquired informally through experiences rather than in a formal classroom learning environment.

Given the impact of HIV and AIDS, and the important role of caregivers, there is a growing need for information and knowledge acquisition by the caregivers for effective intervention in the situation at hand. Information and knowledge obtained help improve caregiving skills and nurture one's expertise in the field.

Against this background, the research study explores the way in which community home-based caregivers of a non-governmental organization obtain information which assists them in effective performance of their tasks.

#### 1.2.1 The context of the area where the research was conducted

The study was conducted in South Africa in the Province of KwaZulu-Natal, in Mpophomeni Township. Therefore, the context of the study area discussed below was the KwaZulu-Natal Province with particular focus on the Mpophomeni Township which is the area where the NGO is located.

## The Province of KwaZulu-Natal

The province of KwaZulu-Natal is said to occupy approximately 92 000 square kilometres, or one-tenth of South Africa's land surface (Census 2011). It is the country's third smallest Province. However, it has the second largest population in the country of approximately 10 456 900, which is about 19.7% of the total population of the country while Gauteng is the province for 12 728 400 (24% of the country) people which makes it the largest. About 43% of KwaZulu-Natal's population lives in urban centres and the rest live in rural areas or semi urban arrears. Rural communities are strongly influenced by traditional authority structures and the communal administration of land and resources. The majority of the population is Zulu-speaking, followed by English and Afrikaans speakers. The province is home to the Zulu monarchy, whose traditional capital is Ulundi whereas Pietermaritzburg is its political or governmental capital. The

province's main centres of urban growth include the port city of Durban that hosts the busiest harbour in Africa, and Richards Bay which is a large industrial area.

Thabethe (2006, p.5) stated that "in their continuous fight against HIV and AIDS, many people within the province have come to realize that HIV is not just a health issue, but a development one as well. Hence, HIV and AIDS must be addressed as a development issue and not exclusively as a health problem." HIV is both driven by factors that are contextual, political, social and economic and also impacts negatively on these contextual realities, deepening already existing vulnerabilities and increasing already existing cultural, socio-economic as well as political impacts.

Below are some of the possible factors that hugely contribute in the continuous rise of the HIV and AIDS pandemic spread based on Barnett and Whiteside's (2002, p.45) observations.

- ➤ Behavioural factors which include multiple sexual partners, serial monogamy, unprotected sexual intercourse, sexual mixing patterns.
- ➤ Socio economic factors such as low literacy levels, the unequal position of women in society; poor access to basic needs (such as housing and access to water); poor access to services (including health, education and welfare); poor access to resources and information).
- ➤ Biomedical factors which include anatomy of women, transmission from mother-to-child during childbirth and breastfeeding, blood transfusion.
- ➤ Macro factors including political, social and economic factors (such as poverty and inequality, low employment rates).

One important issue related to the spread of the pandemic is that of poverty, which is a national challenge since it is not only rife in the province of KwaZulu-Natal but it is across the nation. Therefore, one may argue that poverty remains the biggest threat as it compromises the efforts implemented to curb the spread of HIV and AIDS. Women and girls are said by Thabethe (2006, p.6) to be still vulnerable to risky sexual behaviour, including prostitution and dependency on men for financial benefits owing it to poverty and unemployment. Furthermore, in many of these situations, women fail to assert themselves and negotiate for safer sex through condom usage.

Although male condoms are distributed for free in public clinics, schools, hospitals, toilets, etc., women still find it difficult to access the female condom, which, in contrast, never provided for free (Thabethe, 2006).

There have been several studies on poverty as a factor that exacerbates the spread of HIV and AIDS such as one jointly conducted by the Henry J. Kaiser Family Foundation and Health Systems Trust. In that particular study, Steinberg et al (2002) demonstrate that no sector of the population is unaffected by the HIV epidemic. Nevertheless, the study further demonstrates that it is the poorest South Africans who are most vulnerable to HIV and AIDS and for whom the consequences are inevitably most severe. In that study the households were randomly selected from the client lists of non- governmental organizations providing support to AIDS-affected households in the regions where the survey was conducted. This study reveals a causal link between poverty, HIV and AIDS. It is such study that provokes interest of pursuing studies similar to the current one which takes the issue HIV and AIDS to another level focussing on aspects that fight against the spread of the pandemic such as the literacy of the caregivers of people living with the pandemic.

The following section focuses specifically on the Mpophomeni area (the study's area of focus), highlighting its historical background and outlining some of the socio-economic issues in the area, a discussion that is fundamental and relevant to understanding the current research

# 1.3 The rationale for the study

This section presents three main reasons for conducting the study. The first concerns the importance of the issue. The second relates to the gaps in the scholarship. The third concerns my own interest in the topic.

As more families in South Africa are affected by HIV and AIDS, there is a growing need for assistance with care and support. Increasingly families are faced with coping with the needs of sick members, including assistance with daily living, treatment, and palliative care. Thus households may use one or more support sources that are accessible to them in order to cope with caring for sick family members. Given the limited availability of formal, in-patient

programs, HIV and AIDS-affected families rely upon informal caregivers (for example, family members, friends, community members, or voluntary organizations) and home-based care (HBC) programs for assistance (Homan et al, 2005). Furthermore, Akintola (2008a) state that most of the home-based caregivers are family members of the sick and others are volunteers who have no or little professional knowledge of their jobs.

Interventions to educate families on caregiving are needed as household caregivers may lack the necessary skills for caregiving. This is evidenced by the substantial proportion of caregivers who wish to receive more information and education on caring for people living with HIV and AIDS (Homan et al, 2005). It has been argued by the Department of Health (2005) that the minimal information given to caregivers is usually disseminated in workshops which are conducted by the department and other NGOs once in a while. With this in mind, most of the home-based caregivers' knowledge comes from their informal learning experiences.

Rule and John (2006) argues that the literature on HIV and AIDS had grown at a phenomenal rate and no other or previous epidemic has received as much attention. However, caregiver learning and training has not been given much attention especially in the local South African context. Some, if not most, of the research on caregiver learning and training was conducted internationally (mostly in Canada and United States). Having read so much literature on the epidemic I developed an interest in looking at the way caregivers gain or acquire knowledge and skills that enable them to cope with their duties. The Siyasiza as the context of the study was chosen because of its geographical location which has a rich history relating to the epidemic and the level of literacy. KwaZulu-Natal province is known as the province with the highest level of infection and which might have resulted from violence, political climate, poverty and other factors that have taken place a decade ago.

Therefore, this study was conducted to look at the informal learning experiences of the home-based caregivers supporting HIV and AIDS affected families in KwaZulu-Natal. The study will also give adult educators a better understanding of the importance of informal learning processes hence possibly assisting them in finding ways of supporting the learning experiences of caregivers outside the class room environment or formal educational structures.

#### 1.4 Statement of research focus

My own observations as well as an extensive literature indicate that some families in South Africa are affected by HIV and AIDS, which has left a growing need for assistance with care and support. As a result, families may be forced to utilise one or more support sources in order to cope with caring for sick family members. The high demand on professional governmental and private institutions may force people to take matters into their hands by providing primary care for their sick family members. However, to many families this might be a huge burden and therefore they are forced to seek for external assistance which normally comes from the community home-based caregivers from local non-governmental organisations.

It should be noted that since these organisations assist communities without any expectations of financial benefits, they tend to draw on people who do not have formal qualifications in the field of caregiving. Furthermore, Lave and Wenger (1991) state that inferences have been drawn which suggest that most of what the home-based caregivers know has been gathered informally through workshops or self-directed learning. Therefore, the research focus addressed by the study is the nature of the informal learning experiences of the home-based caregivers supporting HIV and AIDS affected families in a KwaZulu-Natal township and the manner in which learning from these experiences are put into practice to effectively perform daily duties.

# 1.4.1 Research questions of the study

## Key research question:

What are the informal learning experiences of the home-based caregivers supporting HIV and AIDS affected families in a KwaZulu-Natal township?

#### **Sub-questions:**

- ➤ What informs informal learning experiences of caregivers?
- ➤ How are the informal learning experiences made explicit to inform further learning?
- ➤ What do caregivers do with shared information to inform their practices?

### 1.5 Theoretical framework

This study is informed by two interrelated theories, being the theory of situated learning and experiential learning theory, which together make up the theoretical frame work of this study.

# Situated learning

Situated learning is projected by Lave and Wenger (1991) as a model of learning in a community of practice. Hence, this type of learning allows an individual (student/learner) to learn by socialization, visualization, and imitation within the context of a community engaged in a particular practice. Lave and Wenger (1991) argue that learning begins with people trying to solve problems. In support of Lave and Wenger (1991), Anderson, Reder and Simon (1996) are of the view that the theory of situated learning emphasises the idea that much of what is learned is specific to the situation in which it is learned. This means that the potentialities for action cannot be fully described independently of the specific situation. When learning is problem-based, people explore real life situations to find answers, or to solve the problems (Lave and Wenger, 1991). In this study, the home-based caregivers constitute a community of practice whose informal situated learning is explored.

## Experiential learning

Kolb and Fry (1975) stated that experiential learning theory defines learning as the process whereby knowledge is created through the transformation of experience. Thus, according to Kolb (1984) knowledge results from the combination of grasping and transforming experience. Kolb and Kolb (2001) further state that experiential learning is an approach to learning in which participants engage in an activity, reflect on the activity critically, and obtain useful insight and learning. Learning which is developed experientially is "owned" by the learner and becomes an effective and integral aspect of behavioural change (Kolb, 1981).

On the other hand Rogers (1996,p. 140) argues that experiential learning is not just field work or practice, which entails connecting learning to real life situations, but it is a theory that defines the cognitive processes of learning and it asserts the importance of critical reflection in learning.

Some influential researchers in adult education such as Mezirow, Freire and others stress that the way we process experience and our critical response to experience are central to any conception of learning. With this in mind, Rogers (1996) then argues that these authors speak of learning as a cycle that begins with experience, continues with reflection and later leads to action, which itself becomes a concrete experience for reflection. Sternberg and Zhang (2000) argue that the experiential learning theory is a model that portrays two dialectically related modes of grasping experience, Concrete Experience (CE) and Abstract Conceptualization (AC), and two dialectically related modes of transforming experience, Reflective Observation (RO) and Active Experimentation (AE). Kolb (2001) argues that simple skill development, as opposed to simply acquiring knowledge and concepts, occurs through experiential learning.

The combination of these two theories fitted well in my study since they played a crucial role in formulating the research objectives and sub-objectives. Moreover, I used these theories as analytical lenses when the data were analysed. I therefore looked for aspects which best determined or outlined essential elements such as observation, reflection and dialogue which are crucial in the informal learning process. Likewise, during my observation period I used certain indicators that assisted in singling out the importance of the above informal learning elements.

## 1.6 Research methodology

Leedy (1997, p.104) argues that all research revolves around two major approaches, namely quantitative and qualitative, and this study adopted the latter. Since this study sought to understand the experiences of people (home-based caregivers) it was best suited to the qualitative research methodology. Given this qualitative orientation to the data and its analysis I located my study within an interpretevist paradigm with the aim of obtaining a deep understanding of the informal learning experiences of home-based caregivers from a non-governmental organisation in KwaZulu-Natal. This paradigm best suited the study since it explored the richness, depth and complexity of the phenomena that was examined.

## 1.6.1 Research design and methodology

The research is informed by the theories of situated learning and experiential learning where the process of enquiry and learning take place together with a group of home-based caregivers. The aim was to bring an understanding of the informal learning experiences of home-based caregivers from a non-governmental organisation in KwaZulu-Natal. Therefore, a basic qualitative research design was used in order to give the researcher an opportunity to observe, conduct a focus group discussion and in-depth semi-structured interviews.

## 1.6.2 Sampling

For this study the sampling strategy used was a purposeful non-random sample of 12 home-based caregivers of an NGO in KwaZulu-Natal. The selection was made from a pool of 24 employees consisting of home-based caregivers, counsellors and the management of the organisation.

## 1.6.3 Methods of data collection and analysis

These caregivers were observed and then took part in a focus group while six of them were further interviewed using a semi-structured interview. Data gathered was then analysed thematically using the situated and experiential learning theories as lenses.

### 1.7 Delimitation

The delimitations of the study are that it only focuses on the home-based caregivers in one NGO in KwaZulu-Natal hence generalising the results might be a challenge. Furthermore, this study focuses specifically on the informal learning experiences of home-based caregivers rather than the formal or non-formal learning or challenges, roles and other caregiver qualities.

# 1.8 Definition of key concepts

It is important to understand the different key concepts related to this research and the context in which they have been applied. These include the following concepts:

#### Adult education

For the purpose of this study I opted for Houle's (1996, p. 23) definition of adult education which is "the process by which men and women (alone, in groups, or in institutional settings) seek to improve themselves or their society by increasing their skill, knowledge, or sensitiveness; or it is any process by which individuals, groups, or institutions try to help men and women improve in these ways."

## Informal learning

Informal learning is undertaken on one's own; either individually or collectively, without either externally imposed criteria or the presence of an institutionally authorized instructor. Informal learning, then, takes place outside the curricula provided by formal and non-formal educational institutions and programs. Schugurensky (2000) argues that it is important to note that in the concept of "informal learning" researchers deliberately use the word learning and not education, because in the processes of informal learning there are not educational institutions, institutionally authorized instructors or prescribed curricula.

### Caregiver

It has been noted that there are different types of caregivers within the context of community home-base care. Miller (2000) argues that primary caregivers are normally informal carers, including family members and friends, and secondary caregivers could be either the community voluntary caregivers or community health workers who are normally paid by the government or employed by hospices. This study's interest is in voluntary caregivers who are community home-based volunteers recruited, trained and supervised by non-governmental organizations that they work for.

### Community home-based caregiver

Many authors such as van Dyk (2001) and Uys (2003) define community home-based care (CHBC) as care occurring at a patient's residence (community care) to supplement or replace

hospital care (institutional care). Care at home, according to Sims and Moss (1991), involves caring for the patient and those important to him/her as a unit. When it is successful, care provided in the familiar surroundings of the home, with multi-professional input from statutory and voluntary services, can produce the very best of terminal care.

# 1.9 Overview of the study

Having briefly introduced the topic of the study in Chapter One through the research problem, the purpose of the study and the research questions, an overview of subsequent chapters is as follows:

Chapter Two presents a critical review of the literature that gives a general overview of the informal learning experiences of home-based carers. Chapter Three presents and discusses the theoretical framework that informed the study. Chapter Four describes the research approach, including data collection methods and instruments, and discusses matters of validity of specific instruments of the study and procedures of the entire method, as well as ethical consideration. Chapter Five presents the results, discussion and interpretation of the findings of the study. Then Chapter Six concludes the study, and present recommendations that might inform the nature of informal learning experiences of home-based caregivers. This section will demonstrate whether the study has answered the research question.

## 1.10 Summary of the chapter

In this introductory chapter the aim of the study was briefly outlined which to seek deeper understanding of the informal learning experiences of caregivers from a KwaZulu-Natal based NGO. Furthermore, a brief history of the context of the study, rationale for choosing the topic, statement of research focus, the broader issues and the conceptual framework of the study together with the research questions and methods of data collection and analysis were discussed. Lastly, this chapter discussed the delimitations of the study and defined the key terms relevant to the study.

# **Chapter Two**

#### Literature review

### 2.1 Introduction

The first chapter described the research question, the main objective and the sub-objectives of this research. The main objective of this research is to understand the informal learning experiences of home-based caregivers working for a KwaZulu-Natal based non-governmental organisation.

According to Department of Health (2011) community home-based caregivers (especially in rural areas and townships) have proved to be one of the most important pillars of a healthy and progressive nation. This has been driven by the high prevalence of HIV and AIDS and drastic rise of the number of families victimised by the pandemic especially in rural areas. In fighting the high prevalence of this pandemic, a strong force of informed and well trained health personnel need to be in place. However, this is not the battle of the health sector alone but it is for everyone within the affected communities. With this in mind, immediate family members tend to became caregivers even though they lack proper training on caregiving (WHO, 2008). Therefore, the importance of caregiver learning needs to be taken into consideration when dealing with the issues related to HIV and AIDS. Furthermore, when addressing the issue of caregiver learning it is important to identify, support and promote the most suitable learning methods that caregivers can subscribe to.

This chapter covers the literature that is related and relevant to the study. Prytherch (2000) argues that a literature review is a survey of progress in a particular aspect of a subject area over a given period; it may range from a bibliographical index or a list of references, to a general critical review of original publications on the subject covered. On the other hand, Gash (2000, p. 1) defines a literature review as "a systematic and thorough search of all published literature in order to identify as many items as possible that are relevant to a particular topic." Usually the publications reviewed include materials such as theses or dissertations, books, reports and journal articles.

According to Thody (2006) a literature review aims at justifying the research by showing that other researchers have researched the topic or researched it in another way. The literature review pays homage to those who have gone before the researcher and whose work has influenced his/her thinking. Thody (2006) further argues that the purpose of the literature review is to illuminate the current researcher's topic. A literature review also assists in showing how the researcher generated his/her conceptual framework and provides a general overview of the area of his/her research.

Kaniki (2006, p.24) argues that "a literature review involves identifying relevant literature or sources of relevant information (bibliographic access), physically accessing the most relevant literature (document delivery), reading and analysing these works." With this in mind, reading the literature helps the researcher focus on important issues and variables that influenced the research question. This study reviews the literature that relates to informal learning experiences of home-based caregivers from a non-governmental organisation in KwaZulu-Natal.

This chapter explores literature in the field of community home-based care (CHBC), with emphasis on the informal learning experiences of home-based caregivers. There is evidence that much research has been done in the area of community home-based care; but there is limited research done which focuses on the informal learning experiences of caregivers in KwaZulu-Natal. Therefore, it is hoped that this study will make a significant contribution to the existing literature in community home-based care since it specifically seeks to understand the informal learning experiences of home-based caregivers working for a KwaZulu-Natal based non-profit organisation.

This chapter gives a brief description of HIV and AIDS in South Africa by discussing issues such as the impact of HIV and AIDS in Africa, South African communities and more specifically KwaZulu-Natal rural areas. It then discusses the role, importance and challenges faced by community home-based caregivers. Further discussion is on the general statistics of the pandemic, factors related the high prevalence of the pandemic and mechanisms to overcome HIV and AIDS. Moreover, this chapter also discusses the three different types of learning (formal, non-formal and informal learning) that caregivers might engaged in with more emphasis on the

latter since it is the crux of the study. Lastly, this chapter then reviews the views of theorists in relation to the topic of this study through brief discussion of the theoretical framework which informed the study.

# 2.2 Description of HIV and AIDS in South Africa

This subsection outlines and briefly discusses the challenges brought by the HIV and AIDS epidemic to affected families and communities at large. This should be covered by looking at the socio-economic challenges, impact of epidemic on families and civil society's response to these challenges. This subsection give a brief overview of the importance of informal learning experiences of home-based caregivers through a series of different topics that address different issues that calls for caregiver expertise.

The HIV and AIDS pandemic has drawn the attention of researchers like Nampaya-Serpell (2001), Jackson (2002), Killian (2004), Walsh (2006), Richter (2008) and Ndabarora (2009) in the past decade and most of them expressed a need for continuous research on the matters related to this pandemic. However, these researches focused predominantly on the prevalence, incidences and statistics of the pandemic as well as the impact it has had on communities. In contrast, these researchers did not pay much attention to issues like HIV and AIDS prevention and caregiver learning or training which are very vital in fighting the pandemic.

## 2.2.1 Factors related to high HIV and AIDS prevalence in South Africa

One may argue in support of Aitken (2009, p.4) who states that there are a number of factors that drove the HIV/AIDS epidemic in Africa and in South Africa in particular. For the purpose of this study only two factors will be discussed, namely the historical and political climate of the country and poverty. For the purpose of this study historical and political climate refers to the governance and the ruling systems of the past decades prior to the democratic dispensation which is in existence currently. This previous apartheid system controlled the geographic location of people depending on their ethnicity and it further determined the nature of their occupation (Craddock, 2004). In terms of the historical and political climate of this country over the past few decades, the prevalence of HIV and AIDS rose as a result of these two aforementioned factors as

well as other that are not discussed in this study. An example of this is (cited by Aitken, 2009, p.4) is amongst migrant labourers, such as industrial and mineworkers, who were forced to work in cities away from their families for long periods of time. Craddock (2004, p.4) argues that, in the past decade urbanisation in South Africa was largely responsible for this situation, as it encouraged a move away from rural agriculture to industrialised work in urban areas. Therefore, some of these migrants resorted to engaging in sex with commercial sex workers (prostitutes), in the process contracting the virus, and then passing it on to their wives and partners when they returned home. Hence, the behaviour of men results in women and young people being more vulnerable and exposed to the epidemic. In addition to the fore mentioned factors, it has been argued by Bankole, Singh, Woog and Wulf (2001), that behavioural, physiological and sociocultural factors make young people more vulnerable than adults to HIV infection. Naturally and biologically, young people pass through the adolescent stage of human development, which is a time when they usually explore and take risks in many aspects of their lives, including sexual relationships. With this in mind, most of those who have sexual intercourse may change partners frequently or engage in unprotected sex, which increases the risk of contracting HIV and AIDS infection. According to Ndabarora (2009), some researchers suggest that young women in Sub-Saharan Africa specifically South Africa are at much greater risk of contracting HIV than young men. This is said to result from the behaviour, tendencies and practices of young men whereby they tend to have more than one sexual partner whom they then infect with the virus during the intercourse.

Streak (2002) argues that poverty in South Africa is mainly responsible for the vast spread of HIV and AIDS. It should be made clear that poverty is more than just insufficient income or lack of nutritional resources. It also includes a lack of opportunities, lack of access to resources and credit, as well as social segregation (Zuma, 2009). Therefore, poverty is complex, multi-faceted and changes in depth and duration (Guthrie, 2003). Moreover, the rise in the inflation rate in recent years has triggered escalating food prices which have impacted negatively on the wellbeing of the poor and sick people who are in serious need of medication. Craddock (2004, p.6) further argues that conditions of poverty and high levels of unemployment, overpopulation, poor access to sanitation and health care are amongst some of the other broader contributing factors to the high prevalence. Additionally, national and international responses to HIV

prevention and intervention have been so lethargic and dismal, that they have done little to reduce the spread of the syndrome. According to Aitken (2009, p.5), the fact that HIV and AIDS is driven by a vast number of contextual, historical and political factors makes it one of the largest challenges that human beings have ever encountered.

# 2.2.2 The impact of HIV and AIDS on families

According to UNAIDS 2011 report the impact of the AIDS epidemic is seen in the dramatic change in South Africa's general mortality rates. The UNAIDS (2011) report also shows that the overall annual number of deaths increased sharply between 1997, when 316,559 people died, and 2006 when 607,184 people died. This rise is not necessarily solely due to HIV and AIDS but those who are particularly shouldering the burden of the increasing mortality rate are young adults, the age group most affected by the epidemic; almost one-in-three women aged 25-29, and over a quarter of men aged 30-34, are living with HIV in South Africa. The link between the mortality rate and number of people living with HIV in South Africa suggests that AIDS is the principal factor in the overall rising number of deaths (UNAIDS, 2011).

The above statistics indicate that this epidemic caused many destructive challenges for immediate family members of the affected people and the community at large (Department of Health, 2009). One of the destructive social impacts of HIV and AIDS is the increasing number of young parents who die and leave small children behind. Clear evidence of this is the increasing number of orphans, child headed households, other vulnerable children affected by HIV and AIDS and the inability of the extended family system to provide such children with basic needs such as shelter, food, medical care, love and support. Children live in an environment which is forever changing because of the increasing frequency of death in their families.

The rapid spread of the epidemic has caused families to dissolve and leave children with relatives or extended families. A practical example given by Zuma (2009) is that when parents die, they leave their children under the guidance of grandparents or they are left alone and the eldest becomes the head of the home. However, even before the family dissolves, the disease strips them of their assets and breadwinners, resulting in further impoverishment. While most

high-prevalence countries have policies in place to support children orphaned or made vulnerable by HIV and AIDS, few national programmes reach more than a small minority of such children (USAID, 2008). Added to the personal suffering that accompanies HIV infection, the AIDS epidemic in sub-Saharan Africa threatens to devastate whole communities, rolling back decades of development progress (Zuma, 2009). With this in mind, one may highlight that numerous parts of society are broken down due to its impact. The effect of the AIDS epidemic on households can be very severe. Many families lose their income earners. According to Zuma (2009), it has been noticed that in all affected countries, the HIV and AIDS epidemic is putting a strain on the health sector. As the epidemic develops, the demand for care for those living with HIV rises, as does the number of health workers affected.

#### 2.2.3 The impact of HIV and AIDS on women and children

It has been noted that the epidemic has a higher negative impact on women and children. To elucidate, in comparison to men the epidemic has particularly harsh effects on children and mostly women, requiring implementation of scaled-up measures to increase women's independent income-generating potential. Women account for two-thirds of all caregivers for people living with HIV in Africa, and women who are widowed as a result of HIV risk social ostracism or destitution (Aitken, 2009). Furthermore, one should note that enhancing women's financial options helps mitigate some of the epidemic's most harmful effects.

In addressing and enhancing the financial options or capacity of women some initiatives or programmes that will assist and improve their lives should be implemented. According to UNAIDS (2007) about 90% of women participating in microfinance initiatives reported significant improvement in their lives, including improved sense of community solidarity in crises and reductions in partner violence. This means that there are some initiatives or measures taken by women to reduce the burden placed by the pandemic on them. Improving treatment access to women has also played an important role in decreasing the number of dying women due to AIDS—related illnesses; however, treatment access alone will not resolve the social and economic damage caused by the epidemic. What is more important and valuable is increasing the scale and scope of prevention and care programmes which is absolutely critical to long-term

efforts to minimize the epidemic's impact on women and children since they are the most affected groups in the population within the general socio-economic situation in South Africa (UNAIDS, 2007).

It has been noted by many researchers like Aitken (2009), Gilborn, Nyonyintono, Kabumbuli and Jagwe-Wadda (2001) that one of the most important effects of HIV and AIDS on children is emotional stress caused by the sickness or loss of a family member. According to Zuma (2009), another great challenge facing a society with a large number of orphans is to guarantee that children become well-adjusted and valuable members of society. It has been noted that there are, however, a number of impediments to achieving this outcome. Firstly, the psychological impact of parental and educator role model illness and death on children should not be underestimated (Akintola, 2004). In addition Akintola (2004) further argues that there are reports that children cared for by extended family members or fostered out, are stigmatised and discriminated against, as for example, they receive less food than other children and are given more chores. On the other hand, Richter, (2008) argues that other studies have found that children raised without sound role models are more likely to engage in delinquent behaviour with negative consequences for society at large. For example, children may be forced to leave school and take care of their sick parents or relatives, or they may be forced to leave school because they are also not well and, as a result of the fear of being discriminated against within the school environment, they choose to stay at home.

### 2.2.3.1 Psychosocial impact of HIV and AIDS on children

This section addresses the psychosocial impact of the pandemic on children. However, it should be noted that this section is included to show the importance of home-based caregivers' role in addressing these issues that affect children as a results of HIV and AIDS. Furthermore, it should be noted that the study focuses on the informal learning experiences of home-based caregivers which in turn informs the efficiency and effectiveness when performing their duties. Hence, I felt a need to include this section in the current study even though it is not so significant and has no impact or influence on the findings of this research but it is rather a highlight of what caregivers are faced with.

According to Killian (2004) in investigating the psychosocial impact of HIV and AIDS on children, one has to appreciate the importance in determining the type of childhood experienced. Paquette and Ryan (2001) argue that to study a child's development we must look not only at the child and his or her immediate environment, but also at the interaction of the larger environment. It has been noted by researchers like Jackson (2002) and Killian (2004) that many psychosocial issues associated with HIV and AIDS go beyond economic, political and other macro-systemic boundaries. Hence, most children made vulnerable by the epidemic become embroiled in a downward spiral of distress and difficulties that affect multiple aspects of their lives. Nonetheless, orphan-hood is not necessarily the critical point of escalating need. Jackson (2002) argues that long before being orphaned, many children suffer the long-term decline in health of their parents or guardians, reduced family income, and the psychological and material consequences of both. Therefore, HIV and AIDS are expected to root a number of psychosocial impacts to the affected children. Initially, the illness of the infected parent is likely to deprive the child of adequate emotional support, nurturance and care; then, as the disease progresses, the parent's lowered economic productivity and increased medical expenses inevitably course a drop in the resources that are available to meet the child's needs (Nampanya-Serpell, 2001).

It has been noted that childhood poverty plays a vital role in the mortality of a large number of infants in South Africa. Furthermore, increased unemployment rates and the impact of HIV and AIDS on breadwinners within households are among the factors contributing to childhood poverty. Streak (2002) argues that with these factors both on the rise, poverty in childhood is likely to increase as well. According to Bradshaw (2008), increased provision of social grants, extreme wealth inequalities and high unemployment most likely play an important role in poor health outcomes.

#### 2.2.4 General information on HIV and AIDS awareness

The HIV and AIDS pandemic issue still has not sunk well on some people as they view it as a monster killing their loved ones hence some people do not even want to talk about it. Information or issues related to this pandemic are often sensitive and some people are still finding it difficult to disclose (especially those who are positive) their statuses fearing the

possibility of being stigmatised and looked upon as disgrace to their families as well as the community. There are campaigns conducted by the health sector to inform people more about the pandemic giving general and detailed information on the prevention and treatment of the pandemic. The caregiver to some extent plays a huge role in performing this task on a one to one basis which normal assist those who are afraid to publicly participate in initiatives or events related to pandemic awareness. It is therefore, important to include a brief literature relating to prevention.

There is good evidence to suggest that traditional mechanisms and strategies assist with coping, but there is growing concern about the resilience of these systems. On the other hand, Streak (2002) argues that some poor people may be more vulnerable because they have not been taught about HIV and AIDS prevention; because they are compelled to exchange sexual favours for gifts or money; because they cannot afford to buy condoms or to treat other sexually transmitted infections (which facilitate HIV transmission); or because they are struggling just to keep themselves fed, and have little time to worry about less immediate threats like HIV and AIDS. Further than that, poorer people usually have less access to HIV and AIDS counselling and testing facilities and those who are unaware of their infection are more likely to pass it on to their next partners. Conversely, necessary information seems to be the property of the wealthier populations, especially from rich countries, as most of this information is retrieved through ICT channels. Furthermore, information is also mostly written and disseminated in a language that the population at high-risk of HIV/AIDS do not understand. In addition, the price of the treatment is still beyond poor people, and this constitutes a major barrier to prevent HIV/AIDS, especially in developing countries, the researcher suggested. Evidence, according to Wilkinson (1996) in Hammond-Diedrich and Walsh, (2006), suggests that children and youth who live in impoverished conditions are at risk of long-lasting psychological and emotional damage. For this reason, children tend to worry about the sick relative and lack of resources, food and support instead of focusing on shaping their own future. According to Ndabarora (2009) some researchers suggested that, to have a successful prevention program, four principles must be followed namely, tackling risk and vulnerability, putting the young person first, greater gender equity, promoting meaningful participation, and commitment to rights.

Community home-based caregivers face a difficult situation when assisting families affected by HIV and AIDS since they do not get the clear precise number of people who have the diseases in a particular family. This is as a result of people not being willing to disclose their statuses or to some extent people being honestly unaware of their statuses. Furthermore, Ndabarora (2009) argues that the increase in the number of infections in South Africa together with the lack of enforced precautions by government, fuels the fear of infection among health workers, especially those operating in trauma units. This is supported by a study conducted by Hall (2004) that showed that 46.4% of nurses are afraid of infecting their partners and children because of the HIV and AIDS exposure at work. Moreover, confidentiality which results from stigma and discrimination additionally accounts for the increased workload of nurses. Since the HIV and AIDS status of most patients was not known by the nurses in the study conducted by Hall, nurses said that they were driven to apply universal precautions while treating all patients in their care. As a result Hall (2004) further argues that nurses felt that these precautions took more time to administer and affected their productivity. The situation would have been much better had the nurses known their patients' HIV status prior to treatment since they would be on par as to what matters needed to be addressed urgently.

Apart from nurses' fear of contracting the infection, some people receiving health care are positioned to be at risk of being infected through unsafe injections, adding to the already high infection rate experienced in hospitals. On the other hand home-based caregivers are also at a high risk of contracting the infection since they are not professional health workers hence they might not have the necessary equipment to protect themselves or else are not even aware of the precautionary measures to be followed to ensure their safety.

Hall (2004) argues that in low- and middle-income countries, an estimated 40% of all injections are given with injection equipment that is unsafe. Zuma (2009) cited Hall (2004) as stating that recent studies in sub-Saharan Africa and Thailand suggest that unsafe injections are responsible for between 1% and 3% of all HIV infections. Hongoro and McPake, (2004) argue that an estimated 327 000 health care workers throughout the world are percutaneously exposed to HIV and AIDS annually. The highest numbers of workers exposed are reported in sub-Saharan Africa and South-East Asia. Zuma (2009) further argues that in Eastern Africa alone, about 19% of

health care workers are infected by HIV-contaminated fluids that they get exposed to through skin preoccupation annually.

According to WHO (2008), the risk of acquiring HIV from a single percutaneous exposure to a needle contaminated with HIV is about 0.43%. Nonetheless, this is an average figure, and deep injuries or injuries from devices with visible blood carry a higher risk of infection. It has been further argued by the WHO (2008) injuries from sharp objects result in about 200 and 5000 HIV infections among health care workers each year globally, and about 4% of all HIV infections among health care workers arise from occupational exposure. There have been recommendations made by WHO (2008) that cited by Zuma (2009) suggesting that post-exposure prophylaxis be provided as part of a comprehensive, universal health sector prevention package that reduces staff exposure to infectious risks.

Some medical instruments such as needles used to treat HIV and AIDS are dangerous and need those who are exposed to them to know how to use and dispose of such instruments. Generally in rural areas and townships people including those who take care of sick family members do not have proper information regarding the use and disposal of some medical instruments such as needles. This is also a case with some home-based caregivers who just volunteered out of will to assist people affected by the pandemic yet lack insightful knowledge needed to carry out their duties. This is where the importance of informal leaning fits since sometimes caregivers are not offered the opportunity to learn about their jobs (through workshops) or other do not see a need since they will be helping family members.

# 2.3 Care and Support offered to HIV and AIDS affected families

UNAIDS (2006) states that, since more families in South Africa are affected by HIV and AIDS, there is a growing need for assistance with care and support. Increasingly, families are faced with coping with the needs of sick members, including assistance with daily living, treatment, and palliative care. Hence households may use one or more support sources in order to cope with caring for sick family members. With this in mind, the health sector alone offers long term coping strategies or permanent support systems. Therefore, affected households and communities

at large are compelled to provide the support system themselves through primary and community home based caregiving. Given the limited availability of formal, inpatient programs, Homan et al (2005) noted that HIV and AIDS affected families rely upon informal caregivers (for example, family members, friends, community members, or voluntary organizations) and home-based care (HBC) programs for assistance.

According to Poortinga (2006) the family, or in economic jargon the household, has formed the crucial social and economic unit on which most human societies have been based. The extended family safety net has been the most effective community response to the AIDS crisis (Mukoyogo and Williams, 1991). Relatives and friends may provide both moral and material support to the sick on the assumption of future reciprocation and sometimes out of sheer lack of alternative. Preparation of food, work on land or overseeing livestock will be done by another family member or neighbour in addition to their own tasks (UNAIDS, 1999).

# 2.3.1 What is a Caregiver?

When defining and discussing a caregiver one needs to bear in mind that there are different types of caregivers within the context of community home-based care (CHBC). There are various volunteer models and names attributed to health care services related to HIV and AIDS. According to Miller (2000), primary caregivers are normally informal carers, including family members and friends, and secondary caregivers could be either the community voluntary caregivers or community health workers who are normally paid by the government or employed by hospices. The primary caregivers to people living with HIV and AIDS (PLWHA) are family members who reside with the patients. Akintola (2008a) and Ncama (2005) both noted that these people (caregivers) are usually women (mother, grandmother, daughter or a sister) and are generally referred to as family caregivers.

In the healthcare service community-based volunteering is known as home-based care (HBC); community health work (CHW); community family support groups; and child support caregivers. Community home-based care (CHBC) is further defined by Thabethe (2006) as care that occurs at the patient's residence to support hospital care, thus linking both families and

communities to the available healthcare services. On the other hand other authors such as van Dyk (2001) supported by Uys (2003) define community home-based care as care occurring at the patient's residence (community care) to supplement or replace hospital care (institutional care). For the purpose of this study the definition given by Thabethe (2006) was adopted as the most suitable and comprehensive definition to be used throughout the study.

#### 2.3.1.1 Voluntary home-based caregivers

In this study the researcher's interest is in voluntary caregivers (home-based caregivers) who are community home-based volunteers recruited, trained and supervised by a particular non-governmental organisations based in KwaZulu-Natal, Pietermaritzburg. Volunteer caregivers are unpaid individuals who devote their time to assist families with their sick relatives. Akintola, (2008a) argues that these caregivers are usually not family members and most of them work for NGOs or community organizations. Furthermore, volunteer caregivers or community home-based caregivers typically provide support to families. According to Sims and Moss (1991) care at home involves caring for the patient and giving support to those important to him/her as a unit. Such support is said by Akintola (2008b) to be educating family members on how to provide care for the ill and also provide various kinds of support to families with infected members. When it is successful, care provided in the familiar surroundings of the home, with multi-professional input from statutory and voluntary services can produce the very best of terminal care.

Akintola (2004) argues that depending on the policy of the care organization and resources available, volunteer caregivers bathe, clothe, feed, talk to and fetch medication for their patients. This means that volunteer caregivers are expected to provide primary or basic support services which include constant patient observation in order to quickly react to any given situation. Moreover caregivers also assist families access resources needed for effective care of patients. Such resources might be a collection of the relevant documents which address or outline mechanism of copying when affected by the disease. It has been noted by some researchers such as Akintola (2008) and Killian (2004) that many children affected by HIV and AIDS, particularly older children, become the principal caregivers of a dying parent, and see them

through a long and painful illness. Children as a result became young caregivers and provide the basic support to patients of which sometimes may be beyond their capacity. Young caregivers are defined by Becker (2000, p.5) as

children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.

According to Becker (2000), research suggests that girls are more likely to take on all forms of unpaid care work and more of it, than boys; although boys may share responsibilities other than physical care. This trend is assumed by Martin (2006) cited by Gwezera (2009) that boys sometimes feel ashamed, and become confused, about their caregiving role and gender identity. Furthermore, one may argue that it is often culturally and traditionally more acceptable for girls to take on this responsibility.

# 2.3.1.2 The continuum of care

Baumgartener (1989, p51) stated that the continuum of care refers to the range of services available within the health care sector, and to some extent, outside it, available to address health and wellness needs. Baumgartener (1989, p52) argues that "the term suggests a concept of an increasing intensity of care rather than a specific and unvarying list of services". Frail elders might complete the continuum of care by enlisting the services of a home health agency, then progress to assisted living, then enter a skilled nursing facility as their health challenges escalate (Baumgartener, 1989). The arrangement of preventative public health services, primary care outpatient clinics, local general hospitals, and regional hospitals with intensive and specialty care units is another array of the continuum of care.

Theoretically, clients enter care at the lowest level capable of addressing their problem, and advance to higher levels only as their problems become more complex and demanding. For reasons such as the constraints of financial access to care, profit-seeking by providers of care, lack of information to assist clients makes best choices, geographic and cultural barriers, and

other factors, the continuum of care is a theoretical model rather than an actual system of care delivery.

Caregiving, as defined in the Operational Plan for comprehensive HIV and AIDS care, management and treatment for SA (2003) within the context of community home-based care has to ensure a "continuum of care," that is, a swift transition from a HIV positive test result to treatment and care (Thabethe, 2006). On that note Sims and Moss (1991, p.19) quoted by Zuma (2009) recognized the particular role of this continuum of care, which is to offer a multiprofessional team to provide a holistic approach to care for the individual. Ideally, the crux of the team should consist of nurses, a doctor, therapists, a dietician, social workers, counsellors and psychologists, and chaplains and ministers of religion, either to give regular in-put or to be available when needed or wanted (Ncama, 2005). Moreover, in this continuum of care, a voluntary caregiver is also seen as a key role player. Therefore, it is very important to know and understand both the role and challenges that caregivers are faced with in order for the process (continuum of care) to run efficiently and effectively.

It is vital that families affected by HIV and AIDS get assistance from all possible alternatives such as community based organisation dealing with the issues related to the epidemic. In order to keep families motivated to assist their sick members I believe that Home Based Care (HBC) organisations need become involved in the care of affected children in two important ways: by promoting an enabling environment for psychosocial care and support for vulnerable children, and by helping to create an expanded response by families, communities, governments, faith-based organisations and other organisations promoting psychosocial care and support for children. To that end, HBC services can become part of a larger response to orphan care and most particularly, this larger response can help affected children by promoting programmes that support orphans and vulnerable children psychologically, economically and socially (Baumgaterne, 1989). This home-care model aims to provide a continuum of care for PLWHA from diagnosis to death. This includes counselling and support of people who are relatively symptom free, while placing emphasis on palliative and terminal care (Uys, 2003, p.272). Moreover, the model specifically aims at developing a care system that is effective and sustainable in the context of a developing country.

HBC services may also assist in acknowledging children's changing roles since affected children are in a position that demands them to quickly act like adults. Furthermore, HBC services should ensure access to children's rights, creating an enabling environment by building on children's own resources, peer support and involving youth in finding solutions. According to WHO (2002), HBC programmes should encourage talking about death and dying by providing access to education, health, and social services as well as information related to the epidemic.

# 2.3.2 Challenges experienced by caregivers

According to UNAIDS (2012) over 95% of people living with HIV and AIDS (PLWHA) live in lower-income households in developing countries; and, nearly two-thirds of PLWHA globally live in sub-Saharan Africa. Since 1995, antiretroviral therapy has saved 14 million life-years in low- and middle- income countries, including 9 million in sub-Saharan Africa (UNAIDS, 2012).

As programmatic scale-up has continued, health gains have accelerated, with the number of life-years saved by antiretroviral therapy in sub-Saharan Africa quadrupling in the last four years. Experience in the hyper-endemic KwaZulu-Natal Province in South Africa illustrates the macroeconomic and household livelihood benefits of expanded treatment access, with employment prospects sharply increasing among individuals receiving antiretroviral therapy (UNAIDS, 2012, p.12).

It is likely that as the number of those infected with HIV increases, the gap is widening between the demand and availability of health care services. This means that there will be an increased burden or workload on caregivers since the demand for their services will be high. Therefore, the health sector and non-governmental organisations need to play a role as well so that caregivers are not overworked.

Many children affected by HIV and AIDS, particularly older children, become the principal caregivers of a dying parent, and see them through a long and painful illness. Nevertheless, some studies like one by Mall (2002) have shown that the elderly people in homes are carrying a huge burden. Hence, Hosegood and Timaeus (2006) argue that many older people face the

consequences of HIV and AIDS-related illnesses and deaths among their own children and other relatives as well as wider social and economic changes that have occurred as a result of the epidemic. Some studies have shown that the increase in mortality among the children places both social and economic pressures on elderly parents. Therefore, the burden of care for HIV -positive adults and children orphaned by AIDS frequently falls on elderly people (UNAIDS, 2006, p.15).

In support of the above statement is a study conducted by Mall (2002) in Zimbabwe on the impact of HIV and AIDS on the elderly, which found that this problem remains under-reported. Mall's (2002) study revealed a number of difficulties encountered by the elderly who are caring for HIV and AIDS infected individuals, including carrying them, giving them food, bathing them, administering medication, and transporting them to clinics and hospitals. In another study, conducted by May (2003) it appeared that more than 70% of HIV infected individuals were found to be cared for by the elderly whose ages range from 60 and above.

It should be noted that there are many challenges faced by caregivers. However, for this study emphasis has been on only three that the researcher opted to explore and discuss more. The three challenges discussed here relate to space, workload and emotional stress. Firstly, the inadequacy of space and shortage of resource in public health sectors are major challenges. Communities rely on public health clinics because most people cannot afford the medical expenses of private clinics. Therefore, this situation leads to overloading of patients in public health sectors and people will have to be treated in their homes. Secondly, the caregivers have an enormous workload and they also fear that they are at risk of contracting the virus while on duty. Working with HIV and AIDS affected people is not an easy task since it demands confidentiality and a willingness to be at risk of contracting the virus as you assist. Lastly, working with people affected by HIV and AIDS leads to emotional stress and at time one is highly likely to suffer from burnout (Zuma 2006).

### 2.3.2.1 Inadequate space and shortage of resource in public health sectors (in South Africa)

The rapid spread of the pandemic has resulted in a high demand on the healthcare service and that has put a strain on the health care sectors as well as other related parties involved in the struggle of fighting HIV and AIDS. According to Mohammad and Gikonyo (2005) in the past

few years, hospitals have become overcrowded. Hence, the influx of patients in hospitals may influence the quality of care provided. It has come to the Akintola's (2008) attention that the increasing number of patients hospitalised for an extended period of time has stretched the resources of the health care system. As more households are affected by HIV and AIDS, there is a growing need for assistance with care and support at home. Mohammad and Gikonyo (2005) argue that the increasingly, households are faced with coping with the needs of sick members, including assistance with daily living, treatment, physical care and psychosocial support and care. Given the limited availability of formal, in-patient programmes, households rely upon informal caregivers, including children. Therefore, the family structure is regarded as an important factor that pushes some children into involuntary care work. Cullen (2006) cited by Aitiken (2009) argues that with the main mode of HIV transmission being sexual, if one partner is HIV positive, both are likely to be. As a result when one parent dies from an AIDS related illness, there may be no other adult family member to care for the remaining parent when they become sick. The burden of care is therefore falling more and more on the children in the family.

The existing research evidence from previous studies on HIV and AIDS suggests that the reasons why a particular child becomes a carer within any family will be complex and will vary from household to household and from situation to situation. Becker, Aldridge and Dearden (1998) argue that issues such as the nature of the sickness/condition, love, attachment and co-residency, socialisation, a lack of choice and alternatives, low income, family structure, gender, all push or pull some children into unpaid caring roles and help to explain why a child might become, or remain, a carer in any household.

### 2.3.2.2 Caregivers' workload and fear of getting infected by the pandemic

The pandemic has been found to increase the workload of those caring and assisting the ill because of the inadequate support that is available to them. Hence Hall (2004) noted that, as a result of the demands, health care systems challenges have intensified extremely in low income countries. These challenges include mostly the fear getting infected while assisting the sick person and that reduces the motivation to assist from the caregivers. WHO (2008) reports that people providing health care are at potential risk of HIV exposure, depending on whether

adequate universal precautions are implemented. However, there is also fear that people providing care may be exposed to blood from contaminated blood supplies, from needles or instruments used on other people receiving care or, rarely, from the caregiver to the people receiving care during surgery. With the level of exposure that caregivers face, Hall (2004) concluded that they are most commonly exposed to the blood of the people receiving care via accidental injuries from sharp objects such as syringe needles, scalpels, lancets, broken glass or other objects potentially contaminated with blood. Hall (2004) quoted, Wessels (1997) as stating that the increase in the number of infections in South Africa together with the lack of enforced precautions by government, fuels the fear of infection among health workers, especially those operating in trauma units.

#### 2.3.2.3 Emotional stress and burnout

Given the scale of the problems encountered by the health system in South Africa, nurses and caregivers are greatly affected. It has been noted that during the course of their work, they are in regular and prolonged contact with HIV-infected patients who are in the terminal stages of the sickness. Furthermore, caregivers sometimes witness the death of those that they are helping and therefore suffer from emotional and physical stress or discomfort. They are also highly likely to suffer from burnout which is said by van den Berg et al. (2006, p.7) "to encompasses three distinct components. Its first stage is emotional exhaustion, followed by depersonalization, which is used as a coping strategy. Thereafter, one experiences feelings of reduced personal accomplishment."

According to Zuma (2009, p.19) "burnout is, therefore, a combination of negative behavioural, attitudinal and physical changes in response to work-related stress". In line with what Zuma (2009) stated Booysen (2005) had previously argued that burnout is physical, emotional and mental exhaustion caused by involvement in emotionally demanding situations. Furthermore, Booysen (2005) cited Pines and Arrison (1998) who indicated that burnout is said to be specific to work content and results partly from a lack of support from supervisors and co-workers. In support of Maslach and Schaufeli (1993), Booysen (2005) and Zuma (2009), explain that burnout is composed of dynamic processes and systems, including those that are important to

social support and supportive communicative behaviour, within a work group. With that in mind, the conclusion is that the most frequent consequence of burnout is people leaving their jobs, resulting in a situation where human service organisations lose some of their best and most experienced workers. Ainsworth and Fulcer (1981), cited by Booysen (2005) mentioned that the problem of job stress and burnout is of special concern in professional childcare workers; therefore significant contribution comes from the physical and psychological exhaustion experienced by childcare workers in the caring process

Many researchers noted that health care professionals who work with people affected by HIV and AIDS experience burnout from the excessive demands on their energy, strength, and resources. The experience of burnout can be alleviated by the availability of extrinsic coping resources, one of which is social support. Griffin and Christie (2004) argue that support groups with their focus on awareness, shared experiences, supportive and helping relationships, and the emotional consequences of working with people affected with AIDS can help staff manage stress and enhance their capacity and effectiveness to work with these patients.

# 2.3.3 The training and learning processes of caregivers

This study's main aim was to explore informal learning experiences of home-based caregivers (assisting people affected by HIV and AIDS) working for a non-profit organisation based in KwaZulu-Natal. Furthermore, this study is conducted under the principles, guidelines and standard set by School of Education and Development (Adult Education programme) in the University of KwaZulu-Natal. Therefore, it would be essential to give a brief discussion on adult education prior to reviewing and discussion of different types of learning that caregivers are exposed to.

#### 2.3.3.1 Adult education

Education, as argued by Lindeman (1926), is life not a mere preparation for an unknown kind of future living. He further argues that the whole of life is learning; therefore, education can have no ending. Therefore, this new venture is called adult education not because it is confined to adults but because adulthood, maturity defines its limits (Lindeman, 1926). Generally, adult

education is any learning activity that occurs outside the structure of the formal education system and undertaken by people who are considered as adult in their society. On the other hand Courtney (1989) defined adult education as an intervention into the ordinary business of life; an intervention whose immediate goal is change, in knowledge or in competence. An adult educator is thought to be one, essentially, who is skilled at making such interventions. Adult education is the process by which men and women (alone, in groups, or in institutional settings) seek to improve themselves or their society by increasing their skill, knowledge, or sensitiveness; or it is any process by which individuals, groups, or institutions try to help men and women improve in these ways (Houle, 1996, p.23). The fundamental system of practice of the field, if it has one, must be distinguished by probing beneath many different surface realities to identify a basic unity of process.

Knowles (1980, p.25) noted that one problem contributing to the confusion when defining adult education is that the term "adult education" is used with at least three different meanings. Firstly he argues that in its broadest sense, the term describes a process—the process of adults learning. Secondly Knowles (1980, p.25) stated that in its more technical meaning, "adult education" describes a set of organized activities carried on by a wide variety of institutions for the accomplishment of specific educational objectives. In addition, he argues that a third meaning combines all of these processes and activities into the idea of a movement or field of social practice. Thus in this sense, adult education brings together into a discrete social system all the individuals, institutions, and associations concerned with the education of adults and perceives them as working toward common goals of improving the methods and materials of adult learning, extending the opportunities for adults to learn, and advancing the general level of our culture (Knowles, 1980).

Since this is not a genuine or fixed definition of the concept, the researcher opted to cited other researchers such as Indabawa and Mpofu who might have a more insightful and meaningful definition. With this in mind, adult education is said by Indabawa and Mpofu (2006) to have been changed from literacy and remedial education in the 1930s. It is therefore, defined by

Morgan cited by Indabawa and Mpofu, as a system that offers some who were not privileged a last chance to learn. Nafukho, Amutabi and Otunga (2005, p.27) argue that the term adult education denotes

the entire body of organised educational processes, whatever the content, level, method, whether formal or otherwise, whether they prolong or replace the initial education, in schools, colleges and universities as well as in apprenticeship, whereby persons regarded as adult by the society to which they belong develop their abilities, enrich their knowledge, improve their technical or professional qualifications or turn in a new directions and bring about changes in their attitudes or behaviour in a twofold perspective of full personal development and participation in balanced and independent social, economic and cultural development.

According to Darkenwald and Merriam (1982) defining adult education is akin to the proverbial elephant being described by five blind men: it depends on where you are standing and how you experience the phenomenon. Darkenwald and Merriam (1982) pointed out the distinction between adult education and adult learning as an important feature to be considered when defining the adult education concept. People often use these concepts interchangeably and that creates confusion and misunderstanding of both concepts. Adult education can be distinguished from adult learning and it is indeed important to do so when trying to arrive to a comprehensive understanding of adult education. Adult learning is therefore defined by Darkenwald and Merriam (1982) as the cognitive process internal to the learner and it is what the learner does in a teaching – learning process as opposed to what the teacher does. It should also be noted that learning includes the unplanned, incidental learning that is part of everyday life. Thomas (1991) alluded that:

"clearly learning must be concerned with specific learning outcomes and with the processes of learning needed for students to achieve those outcomes. Therefore, education cannot exist without learning. Nonetheless, learning not only can exist outside context of education but probably it is most frequently found there".

Merriam and Brockett (1997, p.7) stated that they define adult education as activities intentionally designed for the purpose of bringing about learning among those whose age, social roles, or self-perception define them as adults. On the other hand, Verner (1962) perceived adult education as the action of an external educational agent in purposefully ordering behaviour into planned systematic experiences that can result in learning for those for whom such an activity is supplemental to their primary role in society, and which involves some continuity in an exchange relationship between the agent and the learner so that the educational process is under constant supervision and direction.

Although Nafukho, Amutabi and Otunga (2005, p.27), gave a broader definition of the concept, it is important to point out that adult education must be considered not as separate learning experience, but as an integral part of lifelong education and learning. Furthermore, when defining and discussing adult education Nafukho, Amutabi and Otunga (2005), used five broad and detailed stages which gave a sound explanation of the concept within the African context. Darkenwald and Merriam (1982) noted that

adult education is concerned not with preparing people for life, but rather with helping people live more successfully. Thus, if there is to be an overarching function of the adult education enterprise, it is to assist adults increase competence, or negotiate transitions in their social roles (worker, parent, retired person), to help them gain greater fulfilment in their personal lives, and to assist them in solving personal and community problems.

It is important to understand that when looking at Nafukho, Amutabi and Otunga's (2005) five stages of adult education, it is clear that adult education is concerned with working with adults to provide them with education essential to their adult lives. Nonetheless, as a profession, adult education could involve equipping youths who are in the process of growing up with skills and knowledge that will be relevant to their lives. This is supported by Nafukho (1998) stating that in contemporary African societies, unemployed youths learn entrepreneurial skills from training institutions to help them become self-employed entrepreneurs. However, some other youth learn skills so that they can voluntarily assist in their communities. For example, most young unemployed people tend to acquire skills such as peer education, counselling and youth

development. These skills can be acquired in various forms: it can be formal, non-formal and informal.

#### 2.3.3.2 Various learning methods that caregivers might use when seeking for knowledge

Authors such Sorin-Peters (2003), Purdy and Hindenlang (2005) and Thabethe (2006) are of the belief that caregivers as adult learners obtain their knowledge and skills mostly in an informal and non-formal method of learning. Since the current study ought to explore the informal learning experiences of caregivers, it therefore wise to discuss and distinguish this concept from the other various types of learning that caregivers may subscribe to. With this in mind, Livingstone (1999; 2001), Eraut (2000) and Sorin-Peters (2003) have noted that informal learning has received considerable attention in adult education. Informal learning is defined by Livingstone (1999) as any activity involving the pursuit of understanding, knowledge or skill which occurs outside the curricula of educational institutions, or the courses or workshops offered by educational or social agencies.

Schugurensky (2000) argues that the category of informal learning includes all learning that occurs outside the curriculum of formal and non-formal educational institutions and programmes. According to Tusting and Barton (2003), informal learning has been used in various ways such as describing the way adults learn outside formal provision, any non-accredited provision, unpremeditated learning, community provision as opposed to that which is provided in a formal educational institution or learning that has not been formally structured.

## 2.3.3.3 Non-formal and formal learning

If we define informal learning as learning that takes place outside formal education and non-formal education, a few words about these two concepts are needed (Schugurensky, 2000). Eraut (2000) defines non-formal learning as learning that is not provided by an education or training institution and typically does not lead to certification. It is, however, structured in terms of learning objectives, learning time or learning support. Non-formal learning is intentional from the learner's perspective. Non-formal learning is further argued by Indabawa and Mpofu (2006) to be any organised, systematic educational activity carried outside the framework of the formal

system aimed at providing selected types of learning to particular sub-group in the population, whether be adults, youth or children. According to Eraut (2000) there is a close relationship between non-formal and informal learning.

Livingstone (2001) argues that the boundary between formal and non-formal becomes whether or not the learner undertakes the learning voluntarily, as in the adult education tradition of negotiated programmes of learning. Non-formal education is usually directed to adults, but children and adolescents may also participate in this sector (for instance, children going to Sunday school; boy-scouts and girl-scouts programs, second language courses, music lessons during the weekend, etc.) (Schugurensky, 2000). On the other hand, Livingstone (2001) argues that when a teacher has the authority to determine that people designated as requiring knowledge effectively learn a curriculum taken from a pre-established body of knowledge, the form of learning is formal education, whether in the form of age-graded and bureaucratic modern school systems or elders initiating youths into traditional bodies of knowledge.

Formal learning is further defined by Chisholm (2005) as a purposive learning that takes place in a distinct and institutionalised environment specifically designed for teaching/training and learning, which is staffed by learning facilitators who are specifically qualified for the sector, level and subject concerned and which usually serves a specified category of learners (defined by age, level and specialism). For this type of education, learning aims are almost always externally set, learning progress is usually monitored and assessed, and learning outcomes are usually recognised by certificates, degrees or diplomas. Moreover, much formal learning provision is compulsory (school education) and usually without alternatives.

### 2.3.3.4 Informal learning

It has to be taken into consideration that the basic terms of informal learning are determined by the individuals and groups that choose to engage in it. Moreover, informal learning is undertaken on one's own; either individually or collectively, without either externally imposed criteria or the presence of an institutionally authorized instructor. Informal learning, then, takes place outside the curricula provided by formal and non-formal educational institutions and programmes but can also occur within these spaces. Schugurensky (2000) argues that it is important to note that

in the concept of "informal learning" researchers deliberately use the word "learning" and not "education", because in the processes of informal learning there are not prescribed by educational institutions, institutionally authorized instructors or official curricula.

Schugurensky (2000) used the terms intentionality and consciousness to develop a taxonomy which identifies three forms (or types) of informal learning: self-directed learning, incidental learning, and socialization. These three terms will be briefly discussed in order to give a clear comprehension of the informal learning concept.

Table 1: Three forms of informal learning (adopted from Schugurensky, 2000)

Form	Intentionality	Awareness
		(at the time of learning experience)
Self-directed	Yes	Yes
Incidental	No	Yes
Socialization	No	No

Self-directed learning is a type of informal learning which has been represented both in a descriptive way (as another way in which adults are distinctive) and prescriptively (as something which should be encouraged in adult learning provision) (Tusting and Barton, 2003). People engage in this type of learning with the intention of achieving a certain objective which they are fully aware of. For example, a group of community women wants to reduce the high levels of poverty through subsistence farming, attend workshops (agricultural), listen to radio talk shows, talking with councillors and potential donors such as business people.

On the other hand self-directed informal learning as argued by Livingstone (2001, p.4) "includes intentional job-specific and general employment-related learning done on your own, collective learning with colleagues of other employment-related knowledge and skills, and tacit learning by doing. This means that people who engage in this type of informal learning have a desire to achieve a specific goal at a given time. Yet again drawing boundaries between types of learning is very difficult". Apprenticeships, as an example made by Livingstone (2001, p.5), often combine pre-established bodies of knowledge and practical experiential learning in complex

interactions between teachers and learners as well as individual learning initiatives, and therefore contain elements of all four basic types of learning. According to Gereluk, Briton and Spencer (1999), supported by Burns (1999) other adult learning activities have tended to be ignored or devalued by dominant authorities and researchers either because they are more difficult to measure and certify or because they are grounded in experiential knowledge which is more relevant to subordinate social groups.

The table below gives possible examples of instances where informal learning can be said as having taken place. This table gives a clear indication of the characteristics of the informal learning context.

Table 2: Examples of the instances where informal leaning mostly applies

## Example

One good example of a self-directed informal learning is studying or learning with a study partner or friend. This type of learning can happen anywhere and at any time as learners engage in a conversation with one another. Here learners might discuss concepts that are normally found in a formal or non-formal learning or they might introduce new ideas on a certain topic.

# Learning context characteristics

- ➤ In this context learning does not occur in a formal setting and it takes place anytime in any environment.
- ➤ This type of learning is often overlooked by many as a valid learning especially during the school years. This might result from the fact that it is the most difficult learning method to quantify or track; nonetheless is essential to a young person's cognitive development.

Livingstone (2001, p.6) argues that conceptions of both self-directed informal learning and informal education to date have been quite insensitive to distinctions between intentional and more diffuse forms of learning. Hence, intentional informal learning and intentional informal training can be distinguished from everyday perceptions, general socialization and more tacit informal earning or training by peoples' own conscious identification of the activity as significant learning or training. With this in mind, Livingstone (2001, p.6) therefore stated that the important criteria that distinguish intentional informal learning and training are the retrospective recognition of both (1) a new significant form of knowledge, understanding or skill acquired outside a prescribed curricular setting and (2) the process of acquisition, either on your own initiative in the case of self-directed informal learning, or with aid of a mentor in the case of informal training, respectively. This is the guideline for distinguishing between intentional informal learning and training and all of the other tacit forms of learning and other everyday activities that we go through.

Incidental learning is defined by Schugurensky (2000) as the learning experiences that occur when the learner did not have any previous intention of learning something out of that experience, but after the experience she or he becomes aware that some learning has taken place. Thus, it is unintentional but conscious. Incidental learning is said by Kerka (2000) to be unintentional or unplanned learning that results from other activities. It occurs often in the workplace and when using computers, in the process of completing tasks (Baskett, 1993 and Cahoon, 1995). According to Cahoon (1995), supported by Rogers (1997), it happens in many ways: through observation, repetition, social interaction, and problem solving; from implicit meanings in classroom or workplace policies or expectations (Leroux and Lafleur 1995); by watching or talking to colleagues or experts about tasks (van Tillaart et al. 1998); from mistakes, assumptions, beliefs, and attributions (Cseh, Watkins, and Marsick 1999); or from being forced to accept or adapt to situations (English 1999). This natural way of learning as said by Rogers (1997) has characteristics of what is considered most effective informal learning situations: it is situated, contextual, and social.

Here is an example of learning that is not intended yet the outcome is realised after the process has taken place. A person is listening to a radio talk show and there is a discussion on how to start one's own small business and a certain government department is offering free lessons on acquiring a loan to start the business. In this case this person might have been listing to the show because he did not have anything to do but at the end he will realise that he has learnt about small business enterprises.

Incidental learning can result in improved competence, changed attitudes, and growth in interpersonal skills, self-confidence, and self-awareness. Incidental learning is often not recognized or labelled as learning by learners or others. Adult learners often do not distinguish between formally and incidentally acquired learning (Mealman, 1993) or prefer incidental learning opportunities to formal ones.

Socialization is said by Clausen (1998) to be a term used by sociologists, social psychologists, anthropologists, political scientists and educationalists to refer to the lifelong process of

inheriting and disseminating norms, customs and ideologies, providing an individual with the skills and habits necessary for participating within his or her own society.

Schugurensky (2000) argues that socialization (tacit learning) refers to the internalization of values, attitudes, behaviours, skills, etc. that occur during everyday life. In explaining socialization an example was made by Livingstone (2001, p.20) stating that

the basic forms of socialization that we experience as young people, when older family members engage with us in many forms of anticipatory socialization that neither we nor they recognize as informal training because they are so incorporated in other activities, such as the various ad hoc day-to-day interrelationships between parents and children through which youths are inducted into the cultural life of their society.

An example learning through socializing is made made Schugurensky (2000, p.5) when he states that in a situation where

residents attend regular neighbourhood meetings in which the professional politician listens to demands and promises favours in exchange for votes; after many years of these practices, the culture of clientelism is rooted in both politicians and residents, but it is so ingrained in everyday practice that people assume that such is the only natural way to do politics.

Macionis (2010) argues that socialization describes a *process* which may lead to desirable or moral, outcomes. Individual views on certain issues, such as race or economics, may be socialized (and to that extent normalized) within a society. Many socio-political theories postulate that socialization provides only a partial explanation for human beliefs and behaviors, maintaining that agents are not blank slates predetermined by their environment. Scientific research provides some evidence that people might be shaped by both social influences and genes. Schugurensky (2000) state that people can became of aware of that learning (resulted for socializing) later through a process of retrospective recognition, which could be internal and or external. A person might not be aware that she or he has leant something from a certain

conversation until someone asks questions about their leanings, provoking retrospective recognition.

The genuine difficulty noted by Livingstone (2001, p.6) in his study of adults' informal learning is that researchers do have to engage in a probing process precisely because most people do not recognize much of the informal learning they do until they have a chance to reflect on it. Thus, it is clear that the informal process may take place when people are not fully aware of its progress. For example, when one takes a trip to a certain place one might learn a few things about that place without any intention of gaining knowledge of that particular place. People do not see or understand the importance of informal learning in their lives but recognise the results or outcomes of these processes. This is simple because of the fact that in this type of learning people gain knowledge incidentally in an unintentional or unplanned learning that results from other activities.

## 2.3.3.5 Studies conducted in a context similar to this study

Researchers such as Purdy and Hindenlang (2005) and Thabete (2006) conducted studies similar to the proposed study. The following studies discussed informal learning elements such as dialogue, reflection and action which will form a focal point of the discussion in this study in order to understand the caregivers' learning experiences.

Purdy and Hindenlang (2005) conducted a study in United the States of America exploring the benefits of a caregiver education and training group on improving communication between caregivers and their aphasic (inability to produce speech as a result of brain damage caused by an injury or disease) partners. The group used an adult learning model and an experiential learning cycle similar to one described by Sorin-Peters (2003). The programme addressed education, communication skills training and to a lesser extent counselling whereby caregivers were responsible for their learning as they initiated the process. However, the primary focus was on the caregiver as the learner, and education and training were conducted in a group setting in order to provide peer learning and support as well as joint problem solving opportunities. The results of Purdy and Hindenlang's (2005) study showed that all caregivers felt that the experience was helpful and beneficial to them. Furthermore, caregivers reported that through

peer learning they have a better understanding of their patients and have grown confidence in using the strategies learnt which improved their facilitation skills. Therefore, this study showed that the informal learning was very important to the caregivers since most of what they leant on their own contributed the most in their jobs. Furthermore, the informal learning processes such as reflection, dialogue and action were described as important elements of the informal learning process. The study showed that reflecting on discussions produce better and clear understanding of previous difficult challenges that the caregivers had encountered.

Thabethe (2006) conducted a study which focused on the training of women volunteers in community home based care in the area of Mpophomeni Township, in KwaZulu-Natal province. The research participants consisted of 10 community home-based care (CHBC) volunteers and their supervisor, 3 CHBC trainers, and 1 counselling trainer. Using a qualitative design, this study examines a specific CHBC training course and how effectively it prepares voluntary caregivers for the challenges experienced in individual homes. The findings of Thabethe's (2006) study revealed that already overburdened and poor people provide the bulk of voluntary services in the area of CHBC. Insufficient training proved to be a challenge since the caregivers were unable to provide quality care for people living with HIV and AIDS without external support from the government and other departments. Even though the study did not vividly show the importance of caregivers 'learning experiences, it can be noted that caregivers relied mostly on their experiences and they also had to learn some of the things on their own. Therefore, it shows that informal learning is very important to caregivers since most of them are adults and informal learning best suits people who initiate their learning (mostly people who know what they want to learn). This study showed that even though the focus was on plan training, the caregivers initiated their own informal learning focusing on specific things that they wanted to know or learn.

In his study Livingstone (2001, p.7) argues that with regards to community volunteer work-related informal learning those who have been involved in organized community work over the previous year (over 40%) devoted about 4 hours a week on average to community-related informal learning. The community-related informal learning activities and the proportions of

community participants involved in them as per Livingstone's (2001) study is depicted in Table2:

Table 3: Caregiver's community Work-related Learning Activities percantage (adopted from Livingstone, 2001)

Community work related activities	Percentage of time spent on each activity
Interpersonal skills	62 %
Communication skills	58%
Social issues	51 %
Organizational/managerial skills	43%
Fund raising	38%
Other technical skills	28%
Other skills	24%

The majority of community work participants indicate that they devote no more than 2 hours per week to related informal learning activities, while less than 10% devote more than 10 hours per week. The relatively low levels of participation in community volunteer work and related informal learning are consistent with the fact that this is the most discretionary type of work in advanced industrial societies and many people simply choose to opt out. This study reveals that the informal learning is mostly for personal knowledge and self-improvement but that improvement might indirectly be work related knowledge especially for people working in social environment such as caregivers. This is because a caregiver's work highly depends on his or her personality and that makes interpersonal skills a major contributor in the effective job performance.

### 2.3.3.6 Conclusion of the training and learning processes of caregivers

Most work-related learning occurs informally and incidentally and is self-directed (Livingstone, 2001, p.19). As one moves from planned and "other-directed" learning to informal learning and

incidental learning embedded in experience, the visibility and distinctiveness of learning as a separate act diminishes.

Even though informal learning is most ideal to adults, formal and non-formal learning are of equal importance in the knowledge acquisition process. For this reason, all three types of learning co-exist because people learn in different ways, in different situations and for different purposes. As for example, in a case of community home-based caregiving, caregivers may undergo a formal short course related to their jobs; come back and share their knowledge or experiences with their colleagues who did not get a chance to attend training and others might learn some of the things through observation. Furthermore, learning styles vary; as Livingstone (2010) argues that the context of learning is often heavily dependent on a clearly defined outcome or exigency and one's goal are often related to a specific need, personal desire or business purpose.

# 3 Summary of the chapter

This chapter reviewed the related literature on the informal learning experiences by community home-based caregivers supporting families affected by HIV and AIDS. Studies conducted on the impact of HIV and AIDS in South African communities were used as background of the study's literature review. Furthermore, the chapter looked at how different scholars perceived a caregiver and the role and challenges faced by these caregivers were determined through a review of various relevant literatures from different studies related or similar to the topic under discussion. Having looked at the caregiver' roles and challenges the researcher then looked at how are they trained and which learning method best suit them. This was achieved by looking at different types of learning and a brief discussion of adult learning.

# **Chapter Three**

#### Theoretical framework

#### 3.1 Introduction

Having reviewed related literature in the previous chapter this chapter will discuss two inter related theories which informed the study and also served as lenses in data analysis.

#### 3.2 Theoretical framework

According to Shields and Hassan (2006), a theoretical framework is used in research to outline possible causes of action or approach to an idea or thought. It can serve as a map that guides an empirical enquiry.

This study will be informed by two interrelated theories, the theory of situated learning and experiential learning theory; the latter informs the core frame work of this study. The choice of these two interrelated theories was informed by the nature of learning that I am interested in which is informal learning. I opted to look at the informal learning experiences of home-based caregivers since I believed, supported by literature, that they (home-based caregivers) mostly gain knowledge and understanding of their jobs by engaging in this type of learning. It is important to note that experience is of crucial importance in this type of learning since the process occurs outside a structured curriculum or institution. On the other hand, environment is also an important factor in this type of learning since it provides a platform for experience to take course. Therefore, situated learning and experiential learning theories jointly provided a sound outline of the importance of the environment where home-based caregivers operate and their daily life experiences while on duty. Combining these two theories was further supported by my understanding through literature that some people may understand or make sense of their experiences by engaging with others and that process occurs in a particular environment (community) whereas others opt for an introspective approach. Normally home-based caregivers are encouraged to share their experiences among each other in order to identify common challenges that they might encounter and also to identify common community needs. In a

process of understanding community needs caregivers informally learn more about their jobs and also gain more knowledge and understanding of the community setting they operate in.

#### 3.3 Situated learning

Our learning through experience happens in various ways, it can be solely based on an individual or through a collective engagement in a community. Therefore, one cannot deliberate more on experiential learning without bringing in to picture the situation in which the process takes place. This therefore brings about the notion that informal learning is situated in a particular environment and that environment is a community setting. As we know, situated learning happens in a community. It is therefore important to briefly outline the correlation or relationship between the theory of communities of practice and situated learning.

One may begin by stating that community of practice theory was developed by social anthropologist Jean Lave and former teacher/organisational consultant Etienne Wenger. It is defined as a social theory of learning which focuses on how people learn through every day informal interaction with significant others, in the course of their shared practices (Lave and Wenger, 1999; Wenger, 1998). Lave and Wenger (1999, p.23) further define a community of practice as a set of relations among persons, activity, and world, over time and in relation with other tangential and overlapping communities of practice. According to John (2009, p.66) Lave and Wenger's (1991) earlier collaborations in developing theory on situated learning gave birth to the notions of legitimate peripheral participation within communities of practice. In the context of this study the community of practice happens when the group of community homebased caregivers visit the families affected by HIV and AIDS. Here the home-based caregivers learn by sharing the experiences acquired while on duty assisting their clients. This process happens in a semi-formal debriefing session that they normally conduct every Thursday. However, they interact with each other daily and share experiences resulting from the family visits and in that way the informal learning process automatically yet not always consciously takes place.

Situated learning is projected by Lave and Wenger (1991) as a model of learning in a community of practice. This type of learning allows an individual (student/learner) to learn by socialization,

visualization, and imitation. According to Lave and Wenger (1991) learning begins with people trying to solve problems. The theory of situated learning put emphasis on the idea that much of what is learned is specific to the situation in which it is learned (Anderson, Reder and Simon, 1996). This means that the potentialities for action cannot be fully described independently of the specific situation. When learning is problem based, people explore real life situations to find answers, or to solve the problem (Lave and Wenger, 1991).

In believing that learning is social, Lave and Wenger (1991) argue that learners who gravitate to communities with shared interests tend to benefit from the knowledge of those who are more knowledgeable than they are. Furthermore, Anderson, Reder and Simon (1996) also said that these social experiences provide people with authentic experiences. When students are in these real-life situations they are compelled to learn. Hung (1983) cited by Lave and Wenger (1991) concludes that taking a problem-based learning approach to designing curriculum carries students to a higher level of thinking. Only if learning is placed at the centre of our experience can individuals continue to develop their capacities, institutions enabled to respond openly and imaginatively to periods of change and the difference between communities become a source of reflective understanding. Learning that takes place throughout an individual's life may not only equip learners with knowledge, but should also address social and ethical issues in society.

Lave and Wenger's (1990) notion of situated learning is supported by Uzzell (1999) and Elliot (1999) who argue that knowledge is generated in authentic community settings and should incorporate social interaction and collaboration in the process. The latter can be achieved through contextual profiling (an outlined view that is dependent on context) which is an epistemology proposed by Brown, Collins and Duguid (1989). They emphasise that the need for an active perception of concepts and representation stems from the argument that "learning and cognition are fundamentally situated" and that we cannot separate

what is learned from how and where it is learned and used. Local investigations and responses in this framework enable learners to situate their learning in what Brown et al. (1989, p.34) refer to as "authentic activities" or the "ordinary practices of the culture" (Jarvis, 2001).

## 3.3.1 Situated Learning Theory's key concepts

This theory has some key concepts which will be very important when collecting and analysing data. These key concepts are:

- Socialization is the means by which social and cultural continuity are attained. Socialization is therefore, a process that may lead to desirable outcomes or undesirable outcomes.
- ➤ Imitation is an advanced behavior whereby an individual observes and replicates another's. The word can be applied in many contexts, ranging from animal training to international politics.
- ➤ Interaction is a kind of action that occurs as two or more objects have an effect upon one another. The idea of a two-way effect is essential in the concept of interaction, as opposed to a one-way causal effect. A closely related term is interconnectivity, which deals with the interactions of interactions within systems: combinations of many simple interactions can lead to surprising phenomena. *Interaction* has different tailored meanings in various sciences.
- ➤ Communication of any sort, for example two or more people talking to each other, or communication among groups, organizations, nations or states: trade, migration, foreign relations, transportation. This process is very important as it results in new information and knowledge gain by those who engage in it. (Jarvis, 2001)

This theory talks about a situation (current experience) which allows learning to happen through actions taken (after reflecting on the discussion about the current situation) in order to solve a particular challenge (practice of the new experience).

# 3.3.2 Critiques of situated learning and communities of practice

I believe that Jean Lave and Etienne Wenger's theory of situated learning has a significant role in our understanding of how people learn through every day informal interaction with significant others, in the course of their shared practices. In their constructive criticism Hodkinson and Hodkinson (2004, p.1) argue that, "this theory is incredibly widely cited, but opinions about the

work tend to polarise, between those who adopt aspects of it fairly uncritically, and those who largely reject it, as being either inadequate or, more charitably, past its sell by date." One of the main reasons why Lave and Wenger's work remains important is that it offers us a starting framework from which to address some of the major challenges faced by the workplace learning literature (Hodkison and Hodkinson, 2004, p.1).

The first line of criticism of this theory is its inability to incorporate wider issues of social and economic inequalities beyond the actual site of learning, fully into analysis of learning. With this in mind, Hodkinson and Hodkinson (2004, p.1) argue that "when researchers approach workplace learning from a social/cultural perspective, there is a tendency to concentrate on the structures, culture and contexts of the workplace itself and whilst this is clearly of great significance, that literature pays much less attention to wider social and economic inequalities, within which the workplace and the workers are enmeshed." Thus this theory doesn't give much attention to the individuals engaging in learning but focus rather on the factors influencing learning and the actual place where the process takes place.

Another criticism of this theory as identified by Hodkinson and Hodkinson (2004, p.3) is an exaggerated emphasis on legitimate peripheral participation as the prime learning process in all situations. Like so many other writers about learning, Lave and Wenger concentrate on the learning of newcomers, in almost all cases young newcomers. Hodkison and Hodknson (2004, p.3-4)

point out that there are two, linked problems with the ways in which Lave and Wenger use the concept of communities of practice, which we examine in greater detail, later. Firstly, despite claims that such communities exist, they fail to describe or analyse communities of practice that are either spatially or socially fragmented. Secondly, and more fundamentally, there is an internal contradiction in the book about whether membership of a community of practice is a prime condition for all learning, or whether communities of practice represent certain conditions in which some learning can flourish.

Hodkinson and Hodkinson (2004) believe that in an attempt to meet criticisms that communities of practice were too loosely defined in the earlier book, Wenger produces a much tighter definition, where a community of practice entails mutual engagement, joint enterprise, and a shared repertoire of actions.

## 3.4 Experiential learning

Experiential learning theory defines learning as the process whereby knowledge is created through the transformation of experience. Therefore, Kolb (1984) argues that knowledge is said to results from the combination of grasping and transforming experience. Kolb and Kolb (2001) further stated that experiential learning is an approach to learning in which participants engage in an activity, reflect on the activity critically, and obtain useful insight and learning. Learning which is developed experientially is "owned" by the learner and becomes an effective and integral aspect of behavioural change (Kolb, 1981). Experiential learning is not just field work or practice, which means connecting of learning to real life situations, but it is a theory that defines the cognitive processes of learning and asserts the importance of critical reflection in learning (Rogers, 1996). Some influential researchers in adult education such as Mezirow, Freire and others stressed that the way we process experience and our critical response to experience are central to any conception of learning. Rogers (1996) then argues that these authors spoke of learning as a cycle that begins with experience, continues with reflection and later leads to action, which itself becomes a concrete experience for reflection. Sternberg and Zhang (2000) argue that "the experiential learning theory is a model that portrays two dialectically related modes of grasping experience, Concrete Experience and Abstract Conceptualization, and two dialectically related modes of transforming experience, Reflective Observation and Active Experimentation." It is then argued by Kolb (2001) that simple skill development, as opposed to simply acquiring knowledge and concepts, occurs through experiential learning.

The above statements are well depicted and explained using a famous model created by Kolb and Fry (1981) out of four elements: concrete experience, observation and reflection, the formation of abstract concepts and testing in new situations; they represented these in the famous

experiential learning circle. Figure 1 depicts the stages of Kolb experiential learning cycle model.

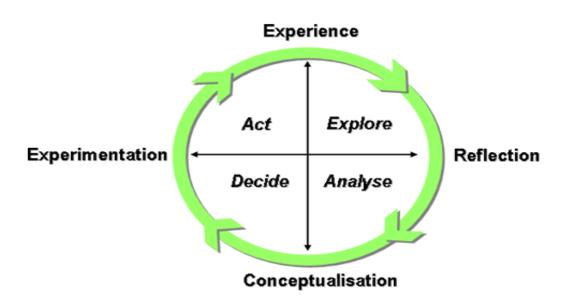


Figure 1: Experiential learning cycle model stages (Kolb, 1984)

Kolb and Fry (1975) argue that the learning cycle can begin at any one of the four points and that it should really be approached as a continuous spiral. However, it is suggested by Lewin (1990) that the learning process often begins with a person carrying out a particular action and then seeing the effect of the action in this situation (experience). Thorpe, Edwards and Hanson (1993) state that immediate personal experience is the focal point for learning, giving life, texture and subjective personal meaning to abstract concepts and at the same time providing a concrete, publicly shared reference point for testing the implications and validation of ideas created during the learning process. According to Kolb's (1999, p.3) four-stage learning cycle depicted in Figure 1, immediate or concrete experiences are the basis for observations and reflections. It is still in the first stage where these reflections are integrated and refined into abstract concepts from which new inferences for action can be drawn. For example, home-based caregivers initiate

their informal learning when they later revisit and reflect on what they have observed and start making sense of it. Hence, these inferences can be actively tested and serve as guides in creating new experiences. Kolb (1999, p.3) further argues that, "in grasping experience some of us perceive new information through experiencing the concrete, tangible, felt qualities of the world, relying on our senses and immersing ourselves in concrete reality". Adult learners, as noted by Sternberg and Zhang (2000), tend to perceive, grasp, or take hold of new information through symbolic representation or abstract conceptualization thinking about, analyzing, or systematically planning, rather than using sensation as a guide. Similarly, Kolb (1999, p. 3) states that in transforming or processing experience some of us tend to carefully watch others who are involved in the experience and reflect on what happens, while others choose to jump right in and start doing things. Thus, people may learn from either their own experiences or from other people's experiences through observation, reflection and dialogue.

Kolb and Fry (1975) argue that following concrete experience would be the second step (reflection) which is to understand these effects in the particular instance so that if the same action was taken in the same circumstances it would be possible to anticipate what would follow from the action. Tusting and Barton (2003) argue that Boud, Keogh and Walker (1985) see reflection as the part of Kolb's cycle that is most important in turning experience into learning. For example, when people share certain ideas related to a specific topic they need to go back to the most important aspect of that topic to get a thorough understanding. For people to test their knowledge or understanding of a phenomenon, it is essential that they revisit or replicate and think about similar incidents related to those phenomena. A further example of the importance of reflection is the case of a student undertaking a course through a formal education system whereby he/she needs to study (recap or revise what had been learnt) before writing a test.

In this pattern the third step would understand the general principle under which the particular instance falls (Kolb. 1984). In support of Kolb, Coleman (1976, p. 52) argues that generalizing may involve actions over a range of circumstances to gain experience beyond the particular instance and suggest the general principle. Kolb (1984) cites Coleman (1946, p. 52) who argued that "understanding the general principle does not imply, in this sequence, an ability to express the principle in a symbolic medium, that is, the ability to put it into words. It implies only the

ability to see a connection between the actions and effects over a range of circumstances." When the general principle is understood, the last step, according to Kolb (1984) is its application through action in a new circumstance within the range of generalization. Lewin (1990) argues that in some representations of experiential learning these steps, (or ones like them), are sometimes represented as a circular movement (see Figure 1). In reality, if learning has taken place the process could be seen as a spiral. The action is taking place in a different set of circumstances and the learner is now able to anticipate the possible effects of the action.

These theories fit well in the proposed study since they played a crucial role in formulating the research objectives and sub-objectives. Moreover, these theories will be used as the lens when the data is analysed. The researcher will therefore look for aspects which will best determine or outline essential elements such as observation, reflection and dialogue which are crucial in the informal learning process. Moreover, during my observation period he I used certain indicators that will assist in singling out the importance of the above informal learning elements.

### 3.4.1Experiential Theory's key concepts

This theory has some key concepts which were very important when collecting and analysing data. These key concepts are:

- ➤ Observation which, according to Devine (2006), is either an activity of a living being, such as a human, consisting of receiving knowledge of the outside world through the senses, or the recording of data using scientific instruments. The term may also refer to any data collected during this study. An observation can also be the way you look at things or when you look at something.
- ➤ Reflection enables us to correct distortions in our beliefs and errors in problem-solving. Critical reflection involves a critique of the presuppositions on which our beliefs have been built. Learning through reflection is defined by Mezirow (1998, p. 186) as "the process of making a new or revised interpretation of the meaning of an experience, which guides subsequent understanding, appreciation and action." What we perceive and fail to perceive, and what we think and fail to think are powerfully influenced by habits of

- expectation that constitute our frame of reference, that is, a set of assumptions that structure the way we interpret our experiences.
- ➤ Reflective Action, understood as action predicated on a critical assessment of assumptions, may also be an integral part of decision making (Mezirow, 1998). Thoughtful action is reflexive but is not the same thing as acting reflectively to critically examine the justification for one's beliefs. Mezirow (1998) argues that reflection in thoughtful action involves a pause to reassess by asking: What am I doing wrong? The pause may be only a split second in the decision-making process.
- Experiment is the step in the scientific method that arbitrates between competing models or hypotheses (Cooperstock, 2009) Experimentation is also used to test existing theories or new hypotheses in order to support them or disprove them (Griffith, 2001). An experiment or test can be carried out using the scientific method to answer a question or investigate a problem. First an observation is made, then a question is asked, or a problem arises. Next, a hypothesis is formed, and then experiment is used to test that hypothesis. The results are analyzed, a conclusion is made.

These concepts were used when collecting data since some of the questions were drawn from them. Moreover, these concepts also played a major role when analyzing data.

### 3.4.2 Criticism of experiential learning theory

Despite the theory's persistent popularity it has been the target of much critical scrutiny. The critics of this theory generally argue that the theory decontextualizes the learning processes and provides only a limited account of the factors that influence the learning. Holman et al (1997), Vince (1998), and Reynolds (1999) all argue that these criticisms converge on the proposition that emphasis on individual experience comes at the expense of psychodynamic, social and institutional aspect of learning. According to Vince (1998), this theory does not adequately consider the context of power relations such as social status, gender and cultural dominance. Furthermore, the theory fails to give ample status to these power differentials on learning. It should be taken into cognisance that Vince (1998) believes that experiential learning theory fails to focus on the "here and now" of experience, instead giving undue status to retrospective

reflection. The theory is further said to ignore the "unconscious" learning process and the defence mechanism that may inhibit learning. Reynolds (1999) echoes such criticisms by suggesting that experiential learning theory promote the individualized perspective of learning at the expense of social and political influences. Critics from the psychodynamics perspective question the nature of learning and suggest relaxing several assumption of the initial theory, including its emphasis on experience and call for greater emphasis on reflective practices in the learning process (Kayes, 2002). Furthermore, Holman et al (1997), view individual learning as a process inseparable from the social and historical position of the learner.

According to Kayes (2002), the second line of criticism proposes a comprehensive rethinking of the experiential learning theory to more explicit account for social learning. Holman et al (1997), reinterpret experiential learning by drawing on Vygotsky's (1978) theory of social learning. Kayes (2002) argues that as an alternative to the fourfold process of experience, reflection, conceptualization and action, a series of literary acts such as rhetoric, argument and social response be used instead.

A third set of criticism focuses on the humanist epistemology of experiential learning. Hopkins (1993) argues a similar point from a phenomenological perspective by proposing that Kolb's structural reductionism and failure to account for the process nature of experience represents an aggressive attack of the process nature of experience in learning. In summary, Kayes (2002) argues that, taken as whole, the criticism of experiential learning theory suggest that the theory's emphasis on centrality of individual experience has come at the expense of psychodynamic, social and institutional aspect of learning. Therefore, the alternatives include an introduction of critical theory, social learning theory, psychodynamic and phenomenology, as well as all out in situational boycotts of the theory itself.

3.5 Situational learning and experiential learning lens in study of caregiver's informal learning experiences.

Situational and experiential learning theories offer much promise for understanding the key components of various learning processes undertaken by adults outside a classroom environment. These theories have proved to be relevant in understanding informal learning and everyday

practice. For better use of these theories in this study several questions can be posed in anticipation of caregiver informal learning experiences data to be considered.

- ➤ What is the importance of socialization in caregiver learning processes and experiences?
- ➤ What is the use of imitation in caregiver learning and how does it contribute in their knowledge gathering process?
- ➤ Is communication a useful tool in information sharing and knowledge transformation? If so how is it important in knowledge transformation?
- ➤ How is interaction a useful concept in understanding and gaining knowledge on what it is to be a caregiver?
- ➤ How important is observation in the informal learning process?
- ➤ How do caregivers engage in reflection?
- ➤ Having got all the required data or information why is it so important to have reflective action?
- ➤ What do caregivers do with their experiment or experiences?

The few questions generated from the theories form the basis of understanding the main key research question sought to be answered or addressed by this study. The data collected using the indicators detected by these theories gave clarity to the sub questions drawn from these two theories and therefore answer the key research questions of the study in the process. Furthermore, with these sub questions taken into cognition when analyzing data in the next chapter the key research question is fully answered.

# 4 Summary of the chapter

In this chapter two interrelated theories which were used as lenses when analysing data were discussed. Situated learning theory highlights that the informal learning process is situated in a particular environment and that environment is a community setting. However, the challenge with communities of practice is the difficulty of clearly defining "community" since there are numerous connotations related to the concept. On the other hand, experiential learning theory points out the importance of observation, dialogue and reflection in the informal learning

process. This theory fails to outline factors influencing learning and also fails to focus on the progress of the experience but instead focuses on the retrospective reflection. These two theories complement each other very well since learners experiences are situated in a particular environment.

# **Chapter Four**

### Research design and methodology

### 4.1 Introduction

This chapter outlines the research methods used in this study, it highlights key differences between two broad categories under which research can be conducted and justifies the chosen research design. Research methodology is defined by Terre Blanche and Durrheim (1999, p.33) as the manner in which a researcher goes about studying what s/he believes can be learnt. The two broad categories under which research is conducted are referred to as quantitative and qualitative research. Babbie and Mouton (2010, p.64) argue that the former refers to studies that are statistical in nature while the latter is normally conducted within the sphere of social sciences and lends itself to a more descriptive format. According to Babbie and Mouton (2001) the methodology section of the study focuses on the processes of research and tools or techniques to be used. The main focus of this chapter is on the research design and methodology that was used to address the research problem. It also focused on the population, different data collection instruments used, namely observation, focus group discussion and in-depth interviews, method of data analysis and issues of trustworthiness, credibility and transferability of the study as well as ethical considerations that need to be noted and obeyed. Since the crux of the study was investigation of the informal learning experiences of home-based caregivers assisting HIV and AIDS affected families, I opted to adopt a qualitative research design, situated within the interpretive paradigm which best suited the nature and objective of the study.

## 4.2 The research setting

In chapter one I discussed the broader context of HIV & AIDS and Home-Based Care in South Africa. In this chapter I discuss the specific setting of Mpophomeni as the context of the study area. This research took place in Mpophomeni, a semi-rural township area in the uMgungundlovu District, uMngeni Municipality of KwaZulu-Natal. The size of this area is 5.10 km² with an estimated population of 21, 139 (4, 145. 82 per km²) people, 11,321 (53%) of which are females and 9.818 (46.44%) are males (Census, 2011). Furthermore, this area is dominated

by Africans (21,079 (99.72%) with only 42 (0.20%) Coloureds and 18 (0.09%) White people. According to Starfish (2010) more that 80% of Mpophomeni residents are unemployed while almost 50% are infected by HIV and AIDS. It is further stated in Starfish (2010) community news that this area is known for high alcohol consumption coupled with high teenage pregnancy.

#### 4.2.1 The context of the area when the research was conducted

The study was conducted in South Africa in the Province of KwaZulu-Natal, in Mpophomeni Township. Therefore, the context of the study area discussed below was the Mpophomeni Township which is the area where the NGO is located.

### Socio-economic status of Mpophomeni residents

I have noticed that like many regions in the different parts of South Africa, some areas of the uMngeni Municipality are marked by substantial wealth, while other people live in terrible poverty. According to the statistics provided from Census (2001), an estimated 7 081 (10%) out of the total population of 73 896 have never had any form of schooling, and this could suggest a high level of illiteracy in the area. It is further reflected that an alarming proportion of 44 887 (60%) of the population do not have any form of income, while 11 536 (16%) of the population are unemployed, with 15 834 (21%) that are not economically active, and these figures could be interpreted as indicating the plight of those communities affected by poverty within the Municipality. This information demonstrates that Mpophomeni is no exception to the realities facing many South Africans, given the high rate of unemployment, poverty, and HIV and AIDS in South Africa, particularly in KZN.

Even though there has not been any substantial statistics on HIV and AIDS specifically for the Mpophomeni area some inferences has been drawn based on some studies such as one conucted by Khumalo (2005). The findings of Kumalo's (2005) study indicated that between 39% and 49% of the people of Mpophomeni are HIV positive. Findings of Kumalo's (2005) study further indicated that people of Mpophomeni started noticing the impact of HIV and AIDS in 1997, though the situation worsened in 2003/2004 as more people became infected. Approximately 30% of the women in the area attending antenatal clinic have tested HIV positive. In the same

report, Kumalo (2005) mentions that 40% of the women who have tested HIV positive were schoolgirls between the age of 13 and 18 years. Despite lack of substantial evidence it was believed that this indicated that a large number of teenage girls who are already infected have intimate relationships with older men. Nonetheless, it should be noted that this situation is not unique to Mpophomeni, but common in poverty-stricken parts of South Africa. For example, Lamptey, Wigley, Carr and Collymore (2002) report on similar occurrences whereby due to poverty and hunger, many young girls of school-going age are forced into dependency roles. They therefore often engage in sexual activities in exchange for food, school fees and clothes as well as any other monetary valued items.

## Historical background of the study area: "Mpophomeni a community of suffering and hope"

The non-governmental organization being explored falls within uMngeni Municipality that was named after the river that runs across Howick and Mpophomeni. According to the study conducted by Kumalo (2005), Mpophomeni is named after the Howick falls. It is believed that "Mpophomeni" is the Zulu word meaning waterfall. During the observation period in our informal discussions one of the home-based caregivers stated that the area of Mpophomeni previously belonged to the Lund family who ran a farm from the 1890s. Moreover, another caregiver stated that the area also had to accommodate farm dwellers who provided labour in the surrounding farms. During the forced removals, Mr. Lund was mandated to relocate to another place so as to create space for black people who were being moved to his farm by the government of the day. Mr. Lund refused to leave his farm, instead he committed suicide. According to the home-based caregivers the first inhabitants of the new township were labourers who had arrived in 1966 for the construction of the Midmar Dam. Hence, the first individual houses were built in 1968, and more houses were constructed in 1972. Eventually, the removals resulted in overcrowding of the Mpophomeni area. Bonnin (1998) argues that the available houses could not accommodate all new arrivals. Kumalo (2005) argues that whenever discussing the history of Mpophomeni area it is vital to mention the problems related to housing in the area since they have a greater impact on the standard of living and the atmosphere surrounding the area.

Poverty is also a reality in the Mpophomeni area as is the situation in many parts of KwaZulu-Natal. In reflecting on the BTR Sarmcol strike, a major strike in the history of South Africa, which took place in 1985, it is not difficult to identify and locate the cause of such high unemployment rate in the community of Mpophomeni. According to the Workers Solidarity Magazine (1999), workers from a British multinational, BTR Sarmcol embarked on a strike after dissatisfaction with their working conditions. Thabethe (2006) argues that the bosses fired all 970 strikers, members of the then Metal and Allied Workers Union, which was not recognized by plant management. Both Kumalo (2005) and the Workers Solidarity Magazine (1999) concurred that BTR Sarmcol was the main industry in the Howick region responsible for the livelihood of many residents in Mpophomeni since 39.5% of the total workforce of Sarmcol came from Mpophomeni. It was discovered by Khumalo (2005) that out of the 970 strikers who were dismissed, 400 were from Mpophomeni. Therefore, the Sarmcol Management decided to employ cheap labour from the neighbouring rural areas.

Bonnin (1998) argues that the community of Mpophomeni was torn apart by the resulting conflict between strikers and the new workers hired by management to replace them. Bonnin (1998) further argues that by the year 1999, 39 people had been killed in fighting related to the dismissals. According to Khumalo (2005), during the same period, Mpophomeni was also hard-hit by the political struggle between two major political parties in KZN at the time, that is Inkatha Freedom Party (IFP) and the African National Congress (ANC). In his reflection, Kumalo (2005) observed how the Mpophomeni people have restored hope in the midst of suffering. Since the political violence in the area lasted for almost 10 years, the people of this community are still in a process of rebuilding their lives to bring about reconciliation.

#### The organisation under investigation

The home-based caregivers that I worked with were from a non-governmental organisation called Siyasiza based in Mpophomeni township of Pietermaritzburg, KwaZulu-Natal. Siyasiza is comprised of 14 caregivers of orphans, 12 home-based caregivers and four counsellors. The organisation offer its services on site and out in the community whereby caregivers visit the

families affected by the pandemic. For the purpose of this study I only worked with the 12 home-based caregivers.

### 4.3 Research paradigm

My understanding of the research paradigm is that it relates to how people view the world or people's assumption about knowledge, reality as well as values. As people we continuously create, interpret, and give meaning to, define, justify and rationalize our actions. Scholars like Henning, Van Rensburg, and Smit (2004, p.24) defined the 'research paradigm' as the framework that supports and forms the basis of the research process. Research paradigm is further defined by Chilisa and Preece (2005, p.43) as the researcher's worldview (ways of thinking about and seeing the world), conceptual framework or theoretical orientation that informs the choice of research problem investigated, the framing of the research objectives, research designs, instruments for collecting data, data analysis and reporting of the research findings.

The current study is allied to the interpretivist paradigm, whereby the understanding of informal learning experiences of caregivers is developed. According to Babbie and Mouton (2006) the interpretivist paradigm emphasizes that all human beings are engaged in the process of making sense of their lives. Hopkins (2000) and Creswell (2003) argue that the interpretivist paradigm seeks an understanding of things within their context and considers the subjective meanings that people bring to their situation. Babbie and Mouton (2006) further argue that according to the interpretivist position, the fact that people are continuously constructing, developing, and changing the everyday (common-sense) interpretations of their worlds, should be taken into account in any conception of social science research. Therefore, for this study understanding is within the context of caregiver learning (specifically informal) experiences.

### 4.4 Research design

According to Merriam & Simpson (1995, p.2) research is "a systematic process of data collection and analysis aimed at discovering something that we did not know before engaging in the process". Hence, an important aspect of research is discovery. A research design as defined by

Mouton (2001, p.55) is "a plan or blueprint of how one intends conducting research". A plan should specify how the research is going to be executed in such a manner that it answers the research question (Terre Blanche & Durrheim, 1999), meaning that the nature of the research dictates the research design.

In planning a research project, Terre Blanche & Durrheim (1999, p.43) point out that a researcher must make decisions regarding all three ways in which types of research are distinguished: (1) exploratory, descriptive and explanatory; (2) applied and basic, and (3) quantitative and qualitative. Terre Blanche & Durrheim (1999) suggest that qualitative research is more commonly used to inductively explore phenomena, and provide thick (i.e. detailed) descriptions of phenomena. Leedy (1997, p.104) argues that all research revolves around two major approaches, namely quantitative and qualitative. Quantitative research as noted by Mouton (2001) generally refers to an objective study that is statistically valid and is normally associated with numerical data. These methods were originally developed in the natural sciences to study natural phenomena (Myers, 1997). According to Falconer and Mackay (1999) this type of epistemology aims at explaining and predicting what happens by looking for relationships between the elements involved. Furthermore, Kim (2003) states that the methodology is characterized by the use of empirical methods that will validate and not influence that which is being examined. Hence, this type of research is conducted under strict, stable experimental conditions, as opposed to natural conditions, while I remain totally neutral. This form of research is logical and involves objective analysis. Kader (2007) argues that more often than not, the quantitative technique is applied in the positivistic approach or post-positivist.

On the other hand, Babbie and Mouton (2001) argue that qualitative research is more subjective; it is more in-depth, exploratory, interpretive and open-ended in nature. Falconer and Mackay (1999) argue that in qualitative research, studies are conducted on entities in their natural settings as opposed to quantitative studies, which are conducted in controlled settings. Qualitative research methods were developed in the social sciences so that researchers could study social and cultural phenomena (Myers, 1997). Maykut and Morehouse (1994) argue that, due to this emergent nature of qualitative research, a qualitative researcher can discover features which were not originally planned for in research design.

Important leads are identified in the early phases of data analysis and pursued by asking new questions, observing new situations or previous situations with a slightly different lens, or examining previously unimportant documents. In this study, I was at the centre of the research, as I was involved in the collection of various empirical materials, which I interpreted in different ways so that I could obtain a better understanding of the data at hand (Denzin and Lincoln, 2003). Therefore, I opted for a qualitative design since it best addressed the purpose of this study, predominantly because of its open, fluid and changeable features as noted in Terre Blanche and Durrheim (1999). Hopkins (2000) and Creswell (2003) state that the research design clarifies the process followed in examining the main objective using various designs and ensures that the findings obtained are aligned to the sub-objectives and thus the main objective. This study's main objective was seeking a deeper understanding of the informal learning experiences of home-based caregivers from a Kwazulu-Natal based NGO. Hence, various processes described by the research design had to be followed in order to gain the understanding.

## **4.4.1 Population / participants**

According to Busha and Harter (1980), population can mean any set of persons or objects that have common characteristics, for example, home-based caregivers from a KZN-based NGO. Population depends on the size of the group or objects about which I plan to make inferences, meaning that the population can be a large group or a small group. A population can refer to people, institutions or objects that have at least one characteristic in common. If the targeted population consists of a large number of units, then sampling needs to be done since I cannot investigate the entire population. In the present study the population to be investigated encompasses 26 caregivers (12 home-based care-givers and 14 cares of orphans) and 4 organisationally based counsellors excluding administrators and directors.

### 4.4.1.1 Sampling

According to Terre Blanche and Durrheim (1999, p.44) sampling involves decisions about which "people, settings, events, behaviours and/or social processes to observe". Furthermore, Terre Blanche and Durrheim (1999) recognized that the main concern in sampling is representation,

that is, the aim is to select a sample that will embody the population from which I aim to draw conclusions. Thus, Maykut and Morehouse, (1994) stated that in qualitative research, participants are carefully selected for inclusion, based on the possibility that each participant (or setting) will expand the variability of the sample. This is known as "a purposeful (non-random) sample, one from which a researcher can learn the most" (Merriam and Simpson, 1995, p.100).

For this study a sample of twelve home-based caregivers was purposefully selected for observation and focus group discussion (all 12 home-based caregivers) while half (six home-based caregivers) of them were randomly selected for in-depth semi-structured interviews. The chosen selection is partially supported by Terre Blanche and Durrheim (1999) in saying that the types of research that are less concerned with statistical accuracy than they are with detailed and in-depth analysis do not draw large or random samples, hence qualitative research which is interpretive in nature. Instead, various types of purposeful (i.e. non-random) sampling may be used. Consequently, Terre Blanche and Durrheim (1999, p.41) recognized that qualitative research aims only to generalize the findings of a study to the specific context under scrutiny in order to assist decision-making in drawing conclusions about the particular problems with which they are dealing: "rather than insisting that samples should be representative, qualitative researchers ensure that their findings are transferable, that is, they help other contexts or groups similar to those studied."

Below is the table that describes how participants were investigated for data gathering purposes

Table 4: Outline of the participants in this study in relation to sub-questions of this study and data collection methods as well as instruments used.

<b>Sub-questions</b>	Method	Source	Instruments
Establish the role of caregivers in communities affected by HIV and AIDS, their challenges and informal learning processes that they engage in as well as experiences.	Review of literature (Chapter two)	Documents	Review
1: What informs informal learning experiences of caregivers?	Observation focus group discussion	12 home based caregivers	Observation guide  Semi-structured open ended questions
2: How are the informal learning experiences made explicit to inform further learning?	Observation  focus group discussion  semi-structured interviews	12 caregivers six HBC (for in-depth interviews)	Observation guide  Semi-structured open ended questions  Semi-structured open ended questions
3: What do caregivers do with the shared information to inform their practices?	Focus group discussion semi-structured interviews	12 caregivers six HBC (for in-depth interviews)	Semi-structured open ended questions  Semi-structured open ended questions

### 4.5 Data collection methods

Data are the basic materials with which researchers work. Chinyemba (2003) argues that once I have identified the information that is required to answer the research question, the next step is to design or adopt an appropriate instrument with which to collect information. In order to get consistent answers to consistent questions, indicators (for observation) and questionnaires should be designed to collect the data for the study. Constructing an appropriate and accurate instrument for measuring and collecting data is absolutely necessary. As noted in the previous section, interpretive researchers maintain that the meaning of a phenomenon varies across contexts, and they adopt a more inductive approach to data collection, investigating how categories of observation emerge in context.

According to Merriam and Simpson (1995) and Terre Blanche and Durrheim (1999) data collection methods frequently favoured by qualitative researchers, which were also employed in this study, include observations, focus groups, interviews, and analyses of written documents. Merriam and Simpson (1995, p.100) argue that these methods: permit rich and detailed observations of a few cases, and allow the researcher to build up an understanding of phenomena through observing particular instances of the phenomena as they emerge in specific contexts.

#### 4.5.1 Observation

Nieuwenhuis (2007) argues that observation is an essential data gathering technique as it holds the possibility of providing us with an insider perspective of the group dynamics and behaviours in different settings. On the other hand, Terre Blanche and Durrheim (1999) argue that participant observation affords me an opportunity to participate in the setting being studied. Consequently, it takes place while things are actually happening, and thus gets me even closer to the action. In so doing, participant observation helps me to understand the group being studied from the inside out.

However, it is vital to consider that when observing there are different observers roles that the researcher can choose from depending on the influence that he or she wants to provide. In the

current study the researcher's role was that of an observer as a non-participant. A basic qualitative study dictates that the researchers become a member or part of the group that he or she is studying in order get precise data for the study.

For the purpose of this study, as argued by Nieuwenhuis (2007), I looked for patterns of behaviour in a particular community to understand the assumptions, values and beliefs of participants and make sense of the social dynamics but I remained uninvolved and did not influence the dynamics of the setting. I wanted to get an understanding of the factors or elements which informs the informal learning experiences of caregivers.

Therefore, this method of data collection was effectively adopted in the investigation of HBC's informal learning experiences since I spent four weeks with the caregivers on site (visited the homes that caregivers had to attend) and took notes on how the conducted themselves when dealing with their clients. During the observation process approximately five families were visited in a day depending on weather conditions. It is important to note, as Bless and Higson-Smith (2000) and Terre Blanche and Durrheim (1999) highlight, that a major weakness in participant observation is that it can be a particularly time-consuming and demanding way of collecting data. However, using this method of data collection provided me an opportunity to take field notes during work sessions, describing in detail what participants did and said. Those notes were used for evaluation which was done at the end of each day to find out if there were new developments on the caregiver's knowledge and understanding of the task at hand.

It should be noted that I also made good use of key informants (some of the caregivers I visited affected families with) throughout the observation process. The key informant is defined by Terre Blanche and Durrheim (1999, p.138) as somebody that I get on with and who is part of and knows the culture being studied. Furthermore, the key informant is perceived as someone who also likes talking and sharing his/her perspectives. These informal conversations took place over tea or lunch, thus opening possibilities to other unexplored phenomena.

#### 4.5.2 Focus group discussion

Focus group discussions is believed by Niewenhuis (2007) to be a useful technique in qualitative research that widens the range of responses given to me by participants because of the presence of other participants and as a result of the debates between the participants. Usually, the discussions focus on a specific topic which participants discuss among each other. According to Powell (1997, p.114), "focus groups are usually scheduled for one session of one or two hours, but it may be necessary to hold more than one session, in some cases". Niewenhuis (2007) argues that debates and conflicts are encouraged since they assist in data generation. For the purpose of this study all twelve caregivers were allowed to share their learning experiences through the focus group discussion. I then explained the process and requested to record the discussion. However for some reason the participants did not want to be recorded leaving me with note taking as the only option to gather data. The focus group discussions enabled me to get an initial understanding of what informs informal learning experiences of caregivers. Hence the HBCs gave some insightful opinions with regards to factors contributing to their desire to learn. Moreover, through the focus group discussion I got an insight of how informal learning experiences are made explicit by caregivers to inform learning for adjusted practices. It is through the focus group discussion that an insight of what do caregivers with the shared information to inform their practices was gained.

#### 4.5.3 Semi-structured in-depth interviews

I adopted a semi-structured interview technique because it was appropriate for the purpose of my study. Freebody (2003) argues that semi-structured interviews begin with a predetermined set of questions, but allow some latitude in the breadth of relevance. Hence, to some extent what is relevant to the interviewee is pursued. Niewenhuis (2007) states that semi-structured interviews are valuable in that they allow the space for researchers to clarify participant's answers and probe further into specific lines of enquiry. For the purpose of this study an in-depth semi-structured interview was administered to six caregivers in order to get more in-depth data to supplement data obtained through the observation and focus group discussions.

In their analysis, Terre Blanche and Durrheim (1999) argue that conducting an interview is a more natural form of interacting with people as researchers get an opportunity to know people quite intimately, so as to really understand how they think and feel. Merriam and Simpson (1995, p.106) define an interview as a "conversation with a purpose". Merriam (1988) quoted in Merriam and Simpson (1995), describes a semi-structured interview as probably the most used method of data collection in qualitative studies in adult education and training. Furthermore, Merriam and Simpson (1995) stated that by using an open-ended format, investigators hope to avoid predetermining the subjects' responses, and hence, their views of reality. It is against this background that the semi-structured interview was found to be best suited in this particular study since one of the major aims of the study was to hear about the experiences and feelings of women voluntary caregivers involved in CHBC.

I conducted semi-structured in-depth interviews with the intension to provide interviewees an opportunity to talk in some depth about their feelings and experiences. This technique allowed the freedom to expand on the topic as they saw fit. As suggested by Seale (1998 cited in Merriam and Simpson, 1995), an interview-guide was prepared beforehand so as to have a sense of the kinds of feelings and experiences that I would want to explore. Most of the questions asked were drawn from the focus group discussions held before the in-depth interviews.

### 4.5.4 Format of the questions

In a questionnaire, questions can be categorized as either open or closed. According to De Vos (1998) for a study of this nature mostly open questions are recommended.

#### 4.5.4.1 Open-ended questions

According to De Vos (1998) an open question gives the respondents an opportunity to express themselves. The open question has advantages when a variable is relatively unknown to me who will be able to explore the variable better and obtain some idea of the spectrum of responses. The disadvantage of open questions is the difficulty in analysis. It is sometimes difficult to interpret the content. De Vos (1998) found that a questionnaire could contain both open and closed questions. Therefore, in such a case I must aim at using as many closed questions as possible,

even though there will always be information which is difficult to generate by closed questions, so that open questions are unavoidable. Since I was conducting a focus group discussion and interviews, the use of open question was vital in obtaining the information required for the purpose of the study. However, open questions were time consuming because the respondents took time expressing themselves when answering questions.

### 4.6 Data analysis

After the data collection was completed, it was sorted and coded, preparing it for analysis. According to Birley and Moreland (1998, p.58) "coding is the process of structuring data into an analyzable format". Collected data need to be presented in a way that make them understandable to me and other readers.

In qualitative research data analysis, the raw data to be analysed are text (words) rather than numbers. The text that qualitative researchers analyse is most often notes from participant observation, transcripts of the interviews and group discussions. According to Check and Schutt (2012) identifying and refining important concepts is a key part of the iterative process of qualitative research. On the other hand Check and Schutt (2012) argue that sometimes, conceptualizing begins with a simple observation that is interpreted directly, "pulled apart", and then put back together. Bairley and Moreland (1998) argue that coding of qualitative data uses either letters, numerals, or alpha-numeric codes to describe the data, which becomes capable of being analyzed without reference to each of the responses of the sample. Given the nature of the research design, data analysis began by identifying themes and relationships. According to Terre Blanche and Durrheim (1999), themes should ideally arise naturally from the data, but at the same time they should also have a bearing on the research question. Therefore in chapter 5, I have used the field notes and interview transcripts to analyze data. Data analysis consisted of constantly looking for similarities and differences, for groupings, patterns and items of particular significance as suggested by Bell (1993) and also by Terre Blanche and Durrheim (1999).

Creswell and Merriam (1998) argue that qualitative data obtained through observation, focus group discussion and interviews can be analysed using a comparative analysis method through a

process of open, axial, and selective coding. Open coding is defined by Bairley and Moreland (1998) as the initial stage where data are analysed through the process of selecting and naming categories where the overall distinctive aspects of the situation that is seen to understand research are described. Secondly, is the axial coding stage whereby categories and sub categories are identified based on their relatedness. This stage aimed at making connections between categories and sub-categories. In order to understand the manner in which these categories relate one need to have a clear understanding of their relationship. On the other hand, selective coding involves the process of selecting, identifying and systematically relating the core category to other categories.

Table 5: stages used in data analysis with regards to comparative analysis method (adapted from Mchunu, 2011)

Coding categories	Actions taken analysing data		
Open coding	Using theoretical framework as lens for dat analysis, keywords that I would consider looking for were specified.		
	Data gathered through observation, focus group discussion and semi-structured interviews were synthesized and emerging and recurring categories were clearly identified.		
Axial coding	➤ Here the categories were compared with the literature and themed through grouping.		
Selective coding	➤ The themes were used as basis for data analysis		

### 4.7 Ethical considerations

This study related to a very sensitive topic which involves HIV and AIDS; therefore, it is very important that I highlight how the ethical issues were addressed. There was a growing need for me to clarify ethical considerations that had to be noted and procedures that had to be followed for success as well as completion of the study.

Moreover, I understood that the caregivers might become emotional and might also suffer from secondary trauma during and after the focus group discussion and interviews. In cases such as post-traumatic stress, I was going to report to the project manager who would then employ the correct procedures that the organisation normally uses for such incidents.

#### Informed consent

When conducting a study involving people the first thing that a researcher needs to get is their consent. Thus for me to arrange interviews with the community home-based caregivers, the starting point was to obtain permission from the management of the organization whose caregivers are investigated. Even after I was granted permission, it was still deemed necessary to gain informed consent from the research participants (home-based caregivers) themselves. Thereafter, I spent quality time with the respondents as a group to highlight the purpose and objectives of the study. Once more, the participants in the study were informed of all aspects of the research, which might reasonably be expected to influence their willingness to participate in the study. The main aim for doing this was to ensure that there were no unfulfilled expectations. Therefore, when participants in the study eventually agreed to participate, their decision was informed by knowledge about the research. I also made it clear from the outset that the respondents were at liberty to withdraw from the study at any given time should they feel that it is no longer conducive for them to participate.

### Confidentiality and anonymity

The process of data collection caused no harm or embarrassment to the participants since I employed the correct data collection instruments that further ensured that the process is stress

free. For the purpose of maintaining confidentiality I have changed the original name of the NGO to Siyasiza.

The participants were guaranteed that all of the information gathered for this research will remain confidential and false names were used to ensure that participants remain anonymous. Furthermore, I informed the participants and their clients (HIV and AIDS affected families) that the discussions held for the purpose of data gathering would be kept confidential as per the principles of the NGO that I was working with. Lastly, participants were informed that the results of the study would be specially used to inform further research and practice.

#### 4.8 Trustworthiness

In a qualitative study the key principle of a good qualitative research is found in the notion of trustworthiness: neutrality of its findings. According to Birley and Moreland (1998, p.41) "validity ensures that data sets collected or items used are pertinent or relevant to the research." In validity the concern should be to reduce the amount of interference by non-relevant or non-valid aspects, such as the language used, the language should not be complex or hinder understanding and answering (Birley and Moreland, 1998, p.41). Ensuring validity can be achieved in a number of ways, one of which is to carry out an initial investigation (a pre-testing study) using the intended data collecting instrument to check the "authenticity and relevance of the data produced" (Birley and Moreland, 1998, p.42).

However, for the purpose of this study validity or trustworthiness was ensured by considering the four following aspects outlined by Trochim (2006). Firstly, credibility that involves establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research. Secondly, dependability is concerned with whether the researcher would obtain the same results if he/she could observe the same thing twice. Here, the researcher is responsible for describing the changes that occur in the setting and how these changes affected the way the researcher approached the study. Thirdly is the transferability described by Trochim (2006) as the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings. In this study the researcher enhanced dependability and transferability by doing a thorough job of describing the research context and the assumptions that are central to the research. Lastly, confirmability is the degree to which the results could be confirmed or corroborated by others (Trochim, 2006). There are a number of strategies for enhancing confirmability and for this study the researcher conducted a data audit that examined the data collection and analysis procedures and made judgements about the potential for bias or distortion.

# 4.9 Summary of the chapter

This chapter described the methodology used in the study by explaining what was done in the study in order to collect data to answer the research questions. I opted to employ a basic qualitative research method to gather data using observation, focus group discussion and indepth semi-structured interviews as data collection instruments. The choice of instruments used was dictated by the nature of the problem under study, which required collection of factual information to describe the informal learning experiences of home-based caregivers from a NGO based in KwaZulu-Natal.

The next chapter will present the finding of the research.

# **Chapter Five**

### **Analysis of Results**

#### 5.1 Introduction

The previous chapter outlined the basic qualitative research approach as the methodology of this study informed by the situated learning and experiential learning theories which served as lenses in data analysis. The main objective of the study was to seek a profound understanding of the informal leaning experiences of community home-based caregivers. In order to gain this profound understanding, three sub-objectives were used to guide the research process. These sub-objectives were to:

- > determine what it is that informs the informal learning experiences that caregivers engage in;
- ➤ find out how the informal learning experiences are made explicit to inform further learning; and
- ➤ determine what caregivers do with the shared information to inform their practices.

When conducting a study, the research design chosen clarifies the process followed in examining the main objective using various strategies and ensures that the findings obtained are aligned to the sub-objectives and thus the main objective. Therefore, in order to fulfil the main objective of this basic qualitative study, which aims at learning from the experiences and stories of the participants, an attempt was made to separate the findings from the interpretation. However, I saw it best to bring together the related literature, theoretical framework and the findings of the current study, in order to see the similarities and differences between the current and other studies conducted under the same topic.

In this chapter, the research findings, as obtained through the situated and experiential learning process, are analysed. I opted for a thematic analysis approach whereby I developed themes based on the relatedness of the categories of data collected using various instruments.

Furthermore, when a theme was analysed, related literature and my theoretical framework were taken into account in order to produce profound findings.

Situated learning as a type of learning allows an individual (students/learner) to learn by socialization, visualization, and imitation whereas experiential learning is an approach to learning in which participants engage in an activity, reflect on the activity critically, and obtain useful insight and learning. These two approaches are not mutually exclusive as informal experiential learning happens within situations of socialization. With this in mind when analysing data, I therefore looked for aspects which best determined or outlined essential elements such as observation, reflection and dialogue which are crucial in the informal learning process.

## 5.2 Development of categories and themes to guide discussion

Table 4 clearly outlined the approach and data collection method employed when attempting to address research sub-objectives, whereas Table 5 outlined stages used in data analysis with regards to the comparative analysis method. The following thematic categories emerged as key to the analysis of data:

- ➤ Learning process
- > Factors influencing learning
- ➤ Role played by the caregivers in their learning
- > Importance of the environment in learning process
- ➤ Information sharing
- ➤ Reflection process
- ➤ Learning outcomes
- ➤ Actions taken after learning

These categories were based on the home-based caregivers' day-to-day experiences obtained while assisting the HIV and AIDS affected family around their community. These broad categories were then further developed into themes by grouping together all related categories.

These themes formed the basis for attaining the profound understanding of the caregivers' learning experiences.

# The developed themes are:

- > Caregivers' biographical information
- > Caregivers' learning processes and role
- > Impact of the environment on caregivers' learning processes
- > Learning outcomes and use of the information gained

In table 6 below there is an illustration of how different categories and themes relate to the subobjectives of this research.

Table 6: The development of themes as the basis for data analysis

CATEGORIES	THEMES	SUB-OBJECTIVES	LITERATURE
Learning processes	Caregivers'	To find out what informs	Training and
	learning processes	informal learning	learning
		experiences of caregivers.	processes of
		To find out how the	caregivers
Reflection process		informal learning	(subsection
Reflection process		experiences are made	2.3.3)
		explicit to inform further	
		learning.	
Factors influencing	Impact of the	To find out what informs	
learning and role	environment on	informal learning	
played by the	caregivers'	experiences of caregivers.	
caregivers in their	learning processes		
learning			
Importance of the			
environment in learning			
process			
Learning outcomes	Learning outcomes	To find out what	
	and use of the	caregivers do with the	
	information gained	shared information to	
		inform application?	
Actions taken after		To establish how the	Care and
learning		informal learning	support offered
		experiences of care givers	to HIV and
		affect the. HIV/AIDS	AIDS affected
		affected families?	families
			(subsection 2.3)

### 5.3 Biographical sketches of the home-based caregivers

The first field visit for this study was undertaken in March 2011 with the aim of establishing a relationship with the caregivers and getting to know and understand the environment they operate in. The nature of the study demanded that the researcher visit the field frequently in order to conduct a proper observation whereby he would participate in the activities conducted by the caregivers. The frequent field visits which continued until September 2012 afforded the researcher enough time to gather as much data as possible for the study.

Generally, the caregivers were literate with a few semi-literate people who volunteered their time assisting families affected by HIV and AIDS. During the observations the researcher got a chance to get to know the home-based caregivers better on a personal level. In this way caregivers' biographical information was obtained for the purpose of this study. However, it has to be noted that, for the purpose of maintaining anonymity, the caregivers were given pseudonyms, as was assured in the informed consent letter that they signed before taking part in the study.

#### Nomasonto

Nomasonto is a woman of 30 years who lives positively with HIV and had never been formally employed. She was born and raised in Mpophomeni Township.

She comes from a family of six children and she is the second child. Her father died when she was six years old and her mother, who was a domestic worker, could only educate Nomasonto up to Standard 9 (Grade 11). One of her younger siblings died of AIDS and her uncle later died from the same disease. After her sibling's death she felt motivated to get involved in AIDS work. At present the family depends on a foster care grant that is received in aid of her two nieces and five nephews.

Nomasonto has previously received non-formal training in community home-based care and bereavement counselling through a one day workshop held in her community hall. She is also one of the women who currently work on a temporary basis for the local clinic in their ARV

rollout programme, and she offers on-going support to HIV and AIDS patients on the CHBC programme run by the local NGO that she is currently involved with.

Nomasonto wants to see her nephews and nieces living a healthy and progressive life and is determined to ensure that it happens. She strives to see her community changing for the better by encouraging other unemployed people to get involved in the initiatives taken to uplift the community's standard of living.

### Charity

Charity is 33 years old and had been a domestic worker in Howick for couple of years. She was the primary caregiver to her uncle who died of AIDS.

She comes from a family of eleven children, six of whom have moved out of the house. When her siblings moved out of the house she decided to stay behind so she could take care of her aging parents who lived on a pension.

Charity only completed Standard 7 (Grade 9) in 1990 and she did not provide reasons for not studying further.

In 2011, she reported that she has been involved in voluntary work for seven years. She saw a great need to care for the sick since she witnessed many people who died with no one to care for them. In terms of HIV and AIDS training, Charity has been trained in both community homebased care and counseling skills by CINDI through short workshops. Charity is one of the women who have been greatly involved in the initiation of the community gardens that assist the sick with vegetables prescribed or recommended by the doctors. She also temporarily works for the local clinic on their ARV rollout programmes, while she continues to offer voluntary care in CHBC.

Charity seeks always to be helpful to the needy and exemplary to the youth in her community. Her personality demands that she assist people who are needy.

I like helping people; this is within me, it is something I grew up with. Since I was a child I have always been involved in voluntary initiatives at my disposal.

### Gugu

Gugu is a 44 year-old woman with vast experience of many years of employment in domestic work. Gugu had two distant relatives who died of HIV and AIDS. Since childhood, she has been helping the sick and the dying and that is why she felt an attraction to get involved in this type of work. She is married with six children and her husband, who is employed, provides for the family.

Gugu finished her matric in 1995 and did ABET (Adult Basic Education and Training) in 2008, fine tuning her language and writing skills, and she is also keen on doing a Bachelor of Education at the University of KwaZulu-Natal.

In terms of HIV and AIDS training, Gugu has been trained in both community home-based care and counselling skills by CINDI through short workshops. She is one of the women who are now in employment at the clinic, providing assistance in the ARV rollout programme. She visits AIDS patients who are about to embark on the ARV treatment programme to check their readiness, using the criteria described above.

### Nompumelelo

Nompumelelo is a 32 year-old woman who comes from a family of nine children, she being the third child. Her father died in 1990 and her mother works two (sometimes three) days a week as a domestic worker. Her cousin died of AIDS in 1997 and her sister died of TB the year after, so Nompumelelo was motivated to get involved in voluntary work. The family's other source of income is the grandmother's pension.

She dropped out of school in Standard 8 (Grade 10) due to financial constraints. One of her brothers also dropped out of school for the same reasons.

She has never been in formal employment. She has only been trained (by CINDI through short workshops) in community home-based care and she is on the same list for a potential job in community health work, as other woman doing voluntary work around the community just like her.

Nompumelo is hoping to become a qualified social worker and also wants to encourage more people to participate in the community caregiving activities. She would like to see her community jointly fight the pandemic and poverty for betterment of the young generation.

#### Silindile

Silindile is 35 years-old, married with three children. She once worked as a domestic worker, looking after an elderly person until she passed away three years back. Both her parents are unemployed pensioners who live in an informal settlement. Her husband is employed as a security guard and earns R1800 a month, which helps to support their family.

Her motivation for getting involved in voluntary work comes from her long-cherished desire to become a nurse. Silindile's dream of becoming a nurse was shattered when she unfortunately failed her matric and decided not write any supplementary exams as she was preparing to get married.

Silindile reported that she has been well trained in community home-based care, counselling, and bereavement counselling by CINDI through short workshops. Regarding her training in CHBC, she disclosed how she was once overwhelmed by the fear of an HIV test, and it was only after her HIV and AIDS counselling training three years later that she decided to go for voluntary counselling and testing (VCT) with her husband. She later remarked how fortunate she was to know her status because she can take care of herself:

knowing your status is a good practice that everyone should follow because it makes things easier when educating your children about the pandemic.

Silindile still believes that she would play a role in fighting HIV and AIDS in her community even if she doesn't become a nurse in future.

#### Zodwa

Zodwa is a 22 year-old young woman who has never been employed. Her father has a drinking problem and fails to support the family. Her mother is also unemployed. She had a sister who died of AIDS.

Zodwa studied up to Standard 9 (Grade 11) when funds did not permit her to further her education. She has been trained in both community home-based care and HIV and AIDS counselling by CINDI through short workshops. I learnt during the final visit that Zodwa had also been temporarily employed by the clinic, which offers the ARV rollout programme.

Unlike the three other voluntary caregivers who decided to continue in CHBC while doing this formal employment, she chose to leave the NGO (which the current study is about) where she was offering voluntary services. When asked about the reasons for getting involved in home care, Zodwa reported that she needed to gain experience in order to get formal employment as she needs to support her family. She also stressed the need to escape boredom and loneliness at home, as she noted:

I find it very boring to sit at home all day doing nothing. Yet again, your needs and interests are ignored and overlooked by those close to you, because you seem useless when you are unemployed.

## 5.4 Caregivers' learning processes

Caregivers' understanding of the concept "learning"

Learning may be viewed and understood in various ways. I see it as any process of skills or knowledge acquisition regardless of form or method used to accomplish this process. Literature points out that the learning process can take place in various forms whereby it can be formal, non-formal or informally conducted (Tusting and Barton, 2003). With the purpose of the study being maintained (focusing on informal learning) and keeping in mind that there are different types of learning, the respondents were asked to give their definitions or view on the concept "learning". Their learning definitions differed in emphasis informed by different contexts and

experiences of learning. It appeared that most of the caregivers subscribed to a similar understanding of the concept "learning" as the process of obtaining knowledge where by one person (teacher) is the orchestrator and producer of the content of the process and one or more (leaners/students) are the recipients or beneficiaries of the process. Zodwa stated that:

if I were to define learning in my own words it would be a method by which people gain knowledge through sharing of information through dialogue or discussion.

#### Gugu said that:

learning is a process by which people gain experience through practice by applying or implementing what they have learnt before.

Inferences may be drawn and conclusions made based on the utterances made by caregivers that, even though they engaged in informal learning, they did not realise that there was such a form of leaning. Rather, they emphasized being taught deliberately for them to learn new things. Furthermore, caregivers gave limited if no signs of understanding of informal learning processes since none of them pointed to or noted the notion of the learner directing the process. However, one may point out that an element of Kolb's (1984) experiential learning model surfaced when one of the caregivers touched on the issue of sharing information while one spoke of gaining experience which happens through reflection and action or practice.

#### Primary and secondary service providers of learning

There are various services that one might subscribe to in order to gain information or knowledge for specific purpose or general self-development. Such services could be formal, non-formal, private or public institutions of learning or individuals who are experts in their fields. A study conducted by Thabethe (2006) shows that caregivers were mostly likely to be members of the organizations that form part of a consortium of approximately 43 HIV and AIDS organizations in the region operating under the auspices of the Children in Distress (CINDI) Network. CINDI normally offers joint training for members of these organizations under the network. However,

this study found that caregivers of the organisation being investigated pointed out that their primary service provider for learning is their team. Hence, most of the knowledge they have comes from their colleagues. This resonates with what Charity stated during the focus group discussion that:

as a team we are solely responsible for our own development since we teach each other where possible.

On the other hand Nompumelelo pointed out that CINDI, government departments such Health and Social Welfare and other privately own companies would be their secondary information or knowledge providers since they only come a few times a year.

Methods of getting information / ways of learning

Information can be obtained in numerous ways using various methods. This section seeks to explore how caregivers went about their processes of learning. According to Brownhill (2001; p.69) Peter Jarvis points out that the state can provide further institutionalized opportunities for learning beyond the school and in the modern world opportunities for learning can be provided on a formal basis by commercial and industrial institutions, which are taken to develop specific skills of their employees for the workplace. In the context of this study, it was found that, besides the government departments' intervention, CINDI normally provided formal and non-formal training to caregivers in a workshop format. This is supported by Thabethe's (2006) study of CHB training which found that these workshops may be one day or two to five days where professionals are invited to facilitate the programme and give certificates. However, this study revealed that not all caregivers attend these kinds of formal trainings but the few who attended have an obligation of transferring what they gained to their colleagues who were left behind to carry the normal daily duties. It was also gathered through focus group discussions that the norm for this organisation is to have a debriefing session every Thursday. During this gathering people share their experiences and new developments as well as the challenges encountered while on duty. Zodwa stated that this session is very important because it does not only provide them with knowledge but also serves as a counselling session for them since they work under stressful and

emotionally demanding circumstances. Nompumelelo also stated that as they visit different people they learn from each visit and in future use the experience gained to solve future challenges. She further added that:

sometimes you surprise yourself when you do things that you never knew you were capable of doing, things just fall into place.

These findings suggest that caregivers' learning processes are informal rather than formal and these processes are self-directed by them through socialization. However, there are also non-formal sessions at CINDI workshops. Furthermore, some of the skills and knowledge are acquired incidentally in different situations. This is supported by Kerka (2000) when she argues that unintentional or unplanned learning results from other activities. Kolb (1984) argues that learning occurs with repetition, practice and incorporation with specific feedback form experienced persons. Thus, caregiver are not expected to use techniques that were simply provided to them in writing or orally. Purdy and Hindenlang (2005) find in their study that the group setting can be a powerful learning mechanism for a person with aphasia and his or her communication partner. These findings are similar to the results of group therapy for individuals with aphasia (Elma and Bernstein-Ellis, 1999a, 1999b), where the supportive atmosphere of the caregiver education and training group fostered bonding to help cope with the consequences of aphasia, and provided means of social and psychological support as it was for the caregivers participated in this study (through or during debriefing sessions).

### Scenarios of informal learning

This section provides a few scenarios of caregivers' informal leaning processes in order to convey a sense of the particular situated texture of caregivers' learning. These scenarios were picked up during our conversations in the time spent observing the caregivers on duty while they conducted family visits.

# Scenario one: Gugu

The first scenario is about Gugu learning about the importance of communication when on duty. Gugu normally visits five different families per day. Two key communication issues arise. Firstly, in these five families we visit we are not welcomed the same way and the patients themselves do not respond the same way to our services. Secondly, HIV and AIDS are very sensitive issues so one needs to carefully choose how to speak about them. Thus communication skills play a huge role on how one effectively performs one's task.

Gugu notes that one of her patients sometimes corrected her during their conversations and told her that it was very important for her to listen more and talk less sometimes:

I was told that even though my job was to give hope and motivation to the sick, sometimes it would be better if I were to listen to my patients speak because that makes them feel like normal people.

Therefore, Gugu took note of the suggestion by her patient and used a different approach when she was with her patients. As a result, her relationship with clients changed and she got to hear more stories from her clients. Gugu further added that:

I have realised that my clients are more open to me and we talk about everything, I mean they confide in me.

As non-participant observer I noted that Gugu knows her clients very well, judging by the way she relates with them. Furthermore, the way she stresses the importance of medication is amazing because she does not force her clients to take treatment but she has a way of telling them politely. I also noticed that the way she relates to adults is not the same as she does to young people. Hence, the manner in which instructions or information is passed to adults is more formal with a lot of respect while with youth she is more informal and sometimes she uses the common slang language that the youth uses. Through dialogue and socialising with her clients

Gugu leant that communication is a key element in caregiving and everyone needs to master it in order to do the job with ease.

### Scenario Two: Nomasonto

The second scenario is when Nomasonto learned how attitude impacts on the way she conduct her duty. As a hard working person who always takes positives from every situation she has faced, Nomasonto cited self-belief, respect and enthusiasm as her pillars of strength when on duty. Just like everyone else, she visits five families per day. Nomasonto said that:

It is very difficult to work with people living with HIV and AIDS because of the sensitivity of their status and stigma attached to it.

She stated that she was talking from experience as she is HIV positive herself and she still finds it difficult to disclose her status to her family and colleagues, since she is afraid that they will judge her and turn their backs on her. Nomasonto said that she had seen people being looked at and treated differently because of their status. However, having spent years as a caregiver made her realise that if she comes with a positive attitude her clients would respond better and open up to her as she gives them hope. Nomasonto explained:

People are not the same and other families do not respond well to our service. Some think we gossip and spread rumours about people's statuses around the community whereas we don't.

### Nomasonto further explained:

During the reflection session my colleagues made me realise the importance of understanding your clients and the manner of approach used when visiting the clients.

As a caregiver it is important to stay professional at all times since we deal with different characters. Patience and tolerance are very crucial aspects when determining quality of caregiver's service.

I have learnt from past experiences that if I had not been a patient person I would not be here today because our job is very tough.

I observed Nomasonto on duty and picked up that she is a good listener who thinks before reacting or responding to a situation. Nomasonto treats every situation differently but always use past experience to determine the outcome of her present situation. Furthermore, she identifies dialogue, socialising and reflection as her most useful learning tools, something which she realised during their debriefing session. She further indicates that the current environment determines how her meeting with the client would unfold since a conducive environment allowed for openness and constructive discussions.

### Scenario Three: Zodwa

The third scenario is about Zodwa, the young aspiring nurse who did not finish her high school and is yet to be employed permanently. Zodwa's learning was two-fold. First, she learnt about the vital importance to clients of taking their medication. Second, she learnt that clients can play an important support role in reminding each other about their medication.

Zodwa had been trained as a counsellor and home-based caregiver and had started working temporarily in the ARV rollout programme at the clinic. The nature of her works dictates that she meet different people every day (especially at the clinic) and these people brought about different challenges which she needed to address. Even though Zodwa was trained she revealed that her training was not enough to help her cope with the actual job. She said that:

when I am on duty the situation is totally different from the training sessions because here patients come with different problems and some have terrible attitude resulting from their suffering (HIV and AIDS).

She further explained that working with people of this nature (PLWHA) is demanding and challenging hence you need to be informed since they will accuse you of making them sick or not wanting them to get well. It is therefore important that one keeps up to date with developments regarding the pandemic and its treatment.

Zodwa stated she had realised that some of her well informed clients help her with a few things when on duty and she is grateful that people listen and trust her with their lives regardless of her age.

Some of my patients always tell me about the importance of making them feel important and normal and they highly appreciated the way I treat them with respect.

Furthermore, some of her clients told her that their lives depends on the medication they take so she should be patient with them even when they give her attitude but she should persevere. Zodwa also realised that clients played a huge role in their health and supported each by reminding one another to take medication.

Moreover, the clinic and the families Zodwa visited offered her a great opportunity to learn new things which help her grow as person and also contribute to her ambitions of becoming a nurse. The time I spent with Zodwa made me realise that she was a committed and dedicated person when it comes to her job and puts her clients first. She further, showed signs of encouragement to her older colleagues, learning a lot from their past experiences, and she also seeks elderly or parental advice from them.

### Actions taken after learning

The current study found that education and training is an on-going process. Taking into account that the current study and other similar or related studies showed that caregivers were most likely to obtain information, knowledge and learn new skills through informal learning processes it is vital that one note the fact that informal learning never ends. Nonetheless, much of it occurs in irregular time and space patterns. For example, you can learn life-course shaping or influencing knowledge at any place and within a very short period of time, in a moment of "perspective transformation", as Mezirow (1991) would call it, or an "organizing circumstance", as termed by

Spear (1988). With this in mind, determining the exact step or action taken after learning turned out to be rather a difficult task since caregivers stated that learning leads to a desire for knowing more.

# Charity mentioned that:

for me it is not easy to determine the immediate action after learning or gaining new information because I have not been noticing my learning behaviour since I am not exposed to any structured learning.

On the other hand, Zodwa, supported by Nompumelelo, stated that once new information is received, she compares it with the related pre-existing knowledge and looks out for similarities or differences and determines the value it adds to her previous experiences. This is in line with Mezirow (1998) and Freire's (2004) argument that the way we process experience and our critical response to experience are central to any conception of learning. Hence, Silindile pointed out that the new knowledge or skill gained leads to practice or application in solving a particular need. She further added that practice might be the sharing process whereby she transfers the knowledge to others and by doing so she also learns more through the feedback given by those whom she dialogues or interacts with.

What I like the most about our debriefing sessions is that refresher element where one gain new ideas and at the same time reminded of what we have forgotten. I also like the fact that these sessions make future decision making and problem solving easier especially when on duty.

Learning opportunities while on duty and actions taken after identification

This study indicated through observation and focus group discussions that a caregiver needs patience so that he or she is able to read and explore the current situation and therefore respond in an acceptable manner. Furthermore, caregivers (who attended the workshops) were actually taught at the training course about the need for patience, perseverance, and humility. Otherwise,

if caregivers do not have these important qualities, they would not be able to exercise tolerance under difficult circumstances in the various homes that they visit.

Nomasonto always stressed the issues of patience and tolerance as she was quoted saying:

As we were told in one of the workshops I attended, patience and tolerance are some of the key elements that make a good caregiver. Through my patience I learnt a lot while on duty since some of my clients share insightful stories when given time and in most cases I gain a lot form these stories.

Livingstone's (2001) study revealed that learning-by-doing is normally the rational way for caregivers when on duty. Though learning is seen as the most prevalent kind of work, learning is also the most invisible and the least documented. Visibility increases where skill formation is the product of a mixture of on-the-job and off-the-job training or of off-the-job training alone. For example, it may be the case that a great deal of home-based caregivers' training occurs in the form of informal education of newer entrants by more experienced health workers, but the relative importance of informal learning without such teachers by workers individually and collectively learning on their own has not been well documented. Furthermore, within the context of Siyasiza only a selected few home-based caregivers had opportunities to attend workshops and they had to rely on their peers for information and knowledge shared during such training sessions. Zodwa said that:

I realised that when working with people there are things that you need to know without being taught. For example, no one will teach you ways of dealing with your clients but some of the things you learn them while on duty. I got to learn that patience and politeness will take you a long way especially when dealing with elderly people who are arrogant and stubborn like some of my clients.

The current study indicated that identification and use of learning opportunities by caregivers while on duty is a process which happens quickly and incidentally. Nomasonto stays:

When first started as a home-based caregiver I didn't know much but as time went on I used my previous visits as a guide to my future visits. Some the people living with the pandemic tend to be very moody and you have to choose your words carefully in order to avoid offending them. I therefore realised after two months that I got a way of breaking the ice when I am with my clients and had gained their trust since they started to be more open to me.

Furthermore, the study also found that by virtue of caregivers being on duty they position or expose themselves to learning opportunities since they said they always learn new things daily during the visits. John (2009, p.66) and Lave and Wenger (1991) argue that earlier collaborations in developing theory on situated learning gave birth to the notions of legitimate peripheral participation within communities of practice. In this study the community of practice happened when the community home-based caregivers visited the families affected by HIV and AIDS. Here the home-based caregivers learnt by sharing the experiences acquired while on duty assisting their clients. They interacted with each other daily and shared experiences resulted from the family visits and in that way the informal learning process automatically yet unconsciously took place.

It is vital to note that caregiver have a responsibility for, and a role to play in their learning process especially when they are aware that learning has occurred. Jarvis (2001, p.70) argues that self-education can also be lifelong, though it has connotations of consciously setting out goals to be achieved rather than a post hoc recognition of the potential education of one's previous random (experiential) learning. Gugu pointed out that they are now forced to make notes during the visits so that they can reflect and report back during a debriefing session. Gugu was quoted as saying:

Debriefing sessions are so important to us since they serve as a refresher workshop if I may say. So it is important for us to note any challenge or important issues that we think it will enlighten others.

# 5.5 Motivation and reasons for caregivers' learning

Motivation is an important factor that informs learning. This section gives a brief discussion on what motivates the caregivers to engage in learning. There are internal or intrinsic motives and external or extrinsic reasons that might trigger the desire to learn.

#### Intrinsic or internal motivation

When asked what inspired her to get involved in helping sick people, Nomasonto revealed that the passing away of her uncle and brother as well as knowing her HIV positive status made her realize the need to help others in a similar situation. Nomasonto's concern is that she currently lives with her boyfriend who does not want to go for HIV testing.

He is the first man I ever slept with and he is also aware of my current HIV status but he tells me that he is not prepared to use condoms. I am aware of the risks, but he feeds and clothes me and also provides for my immediate family, so he is all that I have.

When asked about the source of her motivation to get involved in such work, Charity reported that she enjoys helping other people and she could not imagine herself in any other place except in homes of those who are ill. According to her, she feels called to the kind of work that she is doing:

What would my patients be without me? I am the only person that they share their secrets, pain and joy with because their families and friends have abandoned them, and my faith keeps telling me that that is our calling as people of God.

When asked about the reasons for getting involved in care for the sick, Gugu responded that she gets her motivation from her Christian faith, "Our Christian faith tells us that faith without good deeds is dead." She further explained that the support she gets from her husband is vital:

I am very lucky that my husband is in full-time employment, because he is able to provide for the entire family. The monthly salary of R600 from the Communicable

Diseases Clinic (CDC) only takes care of my cosmetics and covers travel costs of children to school.

On the other hand Zodwa stated that it was simple loneliness and boredom that made her realise that volunteering would be beneficial for her and those receiving her services. She further outlined the issue of independence and being able to think and grow as a person since one cannot stimulate one's mind when doing nothing constructive.

People do not take notice of a person of my age who is just hanging around home and think of you as a failure of which I refused to be characterised as such.

Zodwa said that as a young person of her age she thought to herself that she should be an example to her peers and support HIV and AIDS programmes so that one or two people in a similar situation to her could learn not to give up in life.

Nompumelelo cited the loss of her sister and cousin as a major influence on her volunteering as a community home-based caregiver. Her loved ones suffered during their period of sickness simply because no one had enough information or basic caregiving skills which might have prolonged their lives. She, however, stated that it is very easy to help a person whom you are not related to because they do not think that you are judging and blaming them for the situation they are in.

Silindile pointed to unemployment as the reason she had to do something and that happened to be caregiving in her community. As a married woman with children she saw fit to keep herself occupied with positive matters, contributing to making other people see and realise their relevance and importance in their families regardless of their health status.

Caring for the ill is very rewarding though it is emotionally challenging sometimes. For example, as people we hardly thank each other but when one says the word it means a lot to the one being thanked and gives them motivation and courage to do it to others.

### Extrinsic or External (reasons for learning)

Generally any process or activity has a rationale behind its occurrence, so too the learning process which is undertaken to fulfil a specific goal or desire. Jarvis (2001) argues that human beings are not born as persons, for they can be seen as being in a process of becoming. Jarvis (2001) further stated that the learning experiences people gain and develop can be seen as part of a process that is not only part of the development of their own self-identity, but also incorporates their identity as social beings.

Career-directed learning: Therefore, there are various reasons that may trigger one's desire for learning, such as the case of young Zodwa who did not finish her high school, citing funds as a predicament. Her desires and goals were to become a nurse and all she does now is learning anything that will positively contribute in her becoming a better person in life within her community. As she is still young her dreams have not faded yet she still believes that they can be realised one day and she has learnt a lot in the field of social work, soon joining the clinics where she hopes to learn more about health care. As she explained:

I want to grow and I believe that for me to have a bright feature I need to study and be educated.

Exemplary learning: The veterans in the field of caregiving Gugu and Silindile share the same sentiments. As elderly women of their households, they want to be exemplary to their children and other community members. These two ladies see their desire to learn at their age as a motivation and inspiration to the young people. The decision made by Gugu to attend an ABET course is evidence of how much she values education and self-development. She sees learning as the only tools she can use to fight poverty, empower herself and change the lives of others in her community. Both these ladies are responsible for giving advice to people living with HIV and AIDS and they also teach family members of those infected about how to treat the sick one medically, physically and emotionally. They are also motivated to learn in order to keep up with the new developments regarding the pandemic (HIV and AIDS). Gugu explained:

I always wanted to be a teacher so that I empower myself and community; however, God had other plans as I am now serving his people as a caregiver and a clinic worker (teary eyed and emotionally touched by her own story).

On the other hand, Slindile always transfers her experiences to her children since she always tells them about how she overcame some difficult situations that life had thrown her. As a result she is enthusiastic towards learning something new whenever she gets an opportunity so that her children grow up with vast knowledge that will make them better than her.

Second-chance learning: Beside financial constraints during her teens Nompumelelo never liked school or anything to do with learning; her own learning occurred mostly in formalised structured programmes. What she enjoyed the most was playing with her siblings; school was boring anyway. However, currently she is regretting not using the opportunity and further reflects that, had she showed interest in education, her mother would have supported her at all costs since she is a strong and spiritual woman. Therefore, taking good from bad, she now seizes every possible opportunity she gets and learns as much as possible, though she admits that, while it does not replace wasted chances, it will and has made a difference in her life. Unlike Nompumelelo, Charity did not provide reasons that led her to quitting school in grade 9 and she was not open enough to discuss her leaning profile but all she could say was that "circumstances and the situation at hand at a given time forces me to learn new things or strategies for survival." When asked to give an example she cited her primary caregiving experience when she assisted her uncle during the time when stigmatisation towards PLWHA was high and information on epidemic was also scarce, making it difficult for the untrained primary carers to operate. Hence, Charity's reasons for learning are situational or circumstantial and she can't think of any reason that made or would make her want to learn beside the reasons given above. Just as Gagne (1977) argues, problem-solving is the highest order of learning which happens when a leaner draws on previous situations or experiences in order to discover a solution for a problematic situation. After Charity discovered that she was HIV positive she never disclosed to her family members and colleagues but decided to learn more about the epidemic. This helped her to find peace within herself, hence she is now ready to talk about her status (like she did in this study) and educate more people with or without the illness. She likes to be independent and feel

empowered, that is why she said "learning empowers those who subscribe to it and it enriches them with knowledge generally which separates them from the rest."

Looking at the findings of this study with particular reference to the reasons behind caregivers' learning, it is evident that caregivers subscribed mostly to informal learning processes, bearing in mind that none of them finished their high school. Findings of this study also showed that past *experiences* and current *situations* (part of the study's theoretical framework) mothered the caregivers' reasons for learning supported by pre-existing literature. Jarvis (1995) argues that many people attach importance to the idea that education is a means to getting on in the world. Therefore, people would learn to master a certain skill relevant for a particular job they interested in or simply for self-development as is the case for some caregivers.

These findings indicate that caregivers are motivated by a variety of factors. Common for many is a prior experience of loss and desire to help others. Similarly, in a study conducted by Thabethe (2006), some of her respondents cited loss of their relative as a major motivation to learn and take part in the community home-based caregiving. For some this is based on faith commitments, for others a desire to keep busy and find worthwhile employment.

# 5.6 Impact of the environment on caregivers' learning process

#### Environment

Some people opt to become caregivers simply because there are no complex entry requirements for the job and one can always learn by doing. It was then found in the current study that caregivers found working with PLWHA as a platform for informal learning rather than a formal learning. Moreover, caregivers felt that an environment that allows one to explore and share past experiences is conducive for future and further learning. It was also gathered during the discussions that caregivers felt that learning processes within a rural background are different to those which occur in urban areas since the latter has better infrastructure and facilities that promotes and encourage learning. For example, the availability of community information centres, parks and other edutainment facilities play a pivotal role in triggering desire to learn. Charity believes that if they were to have proper infrastructure or resources that would help them

develop some skills and self-enrich themselves, life would be better for them. Charity was supported by Gugu:

I believe if I were to be placed in an well-resourced community my job will be easier because I will have access to lot of information and have plenty opportunities to learn more about my job as well as other aspect of life.

I found that the group discussion we had was also a learning platform for some since I had some confessions such as one by Silindile;

today I have learnt that learning is a continuous process which also happen unconsciously even during any casual conversation.

Besides Silindile, most of the caregivers agreed to the fact that there is a lot that they have leant though they cannot give details of how the processes occurred.

It was noted by Lave and Wenger (1991), supported by Uzzell (1999) and Elliot (1999), that knowledge is generated in authentic community settings and should incorporate social interaction and collaboration in the process. This notion simply suggests that what has been leant cannot be separated from the way it was learnt and where the process took place.

Griffin and Brownhill (2001, p.57) argue that Torsten Husen predicted that the learning society would be a knowledge and information society. He also made predictions that have become commonplace assumptions about society since, such as the movement towards equal opportunities, and the shift from the manufacturing to service industry as the basis of production. Indeed service rendering has become a common practice which is in demand. For example, caregiving services are in high demand these days in many societies. Therefore, knowledge generation and information sharing would be key tools for survival in societies of life-long learners.

Livingstone (2001, p.19) argues that "the few ethnographic studies that have looked more closely at the workplace as a site of learning have found extensive informal social learning among

manual workers about their work practices, styles and local knowledge beyond individual skills (Kusterer 1978; Darrah 1992; Darrah 1995)." It is also important to note that the nature of the environment where one is situated shapes how people learn. This study showed that most of the knowledge and skills that caregivers have was largely owed to the environment, since these skills and knowledge were informally learnt through practice during the family visits. Nevertheless, Livingstone (2001, p.19) states that, "much of this informal learning is unrecognized and taken for granted by workers themselves most of the time, almost invariably beyond the comprehension of management, and very often collective rather than individual learning."

Thus the environment contributed in the way caregivers learnt in such a way that the challenges encountered and solutions used during the family visits were useful in their future visits.

Factors influencing learning and factors affecting information acquisition

The nature of the job one does also has a huge influence in his or her learning. Nompumelelo stated that working as a caregiver for PLWHA in a community such as hers where stigma towards the infected is so high you need to be informed so that you calmly comfort those you work with. Furthermore, with new developments (on the pandemic) almost every day one needs to be informed and learn as much as possible. In this study it was found that age plays a big role in motivating one to engage in learning.

The study further revealed that people's past experiences influence future learning such as the case of Gugu who passed her matric and never got a chance to further her studies but at a later stage she managed to do ABET.

The first thing that struck me during the focus group interviews with home-based caregivers was the overwhelming importance of confidence. Much learning at work occurs through doing things and being proactive in seeking learning opportunities, and this requires confidence. Moreover, I noted that confidence arose from successfully meeting challenges in one's work (visiting multiple families and making an impact), while the confidence to take on such challenges depended on the extent to which learners felt supported in that endeavour. This links to Eraut's (2000, p.30) argument that there is a triangular relationship between challenge, support and

confidence. If there is neither a challenge nor sufficient support to encourage a person to seek out or respond to a challenge, then confidence declines and with it the motivation to learn. Eraut (2000, p.30) then argues that "the contextual significance of the word "confidence", which was used by our respondents without further elaboration, depended on which aspects of this triangular relationship were most significant for particular people at particular points in their careers." It is not a general attribute like "self- esteem".

For some respondents like Silindile, however, confidence related more to relationships than to the work itself. Silindile says:

When you have support from your colleagues it becomes easier to do your job because you have that confidence which becomes a source of strength. Having good relationship with your colleagues and clients is important because it makes me perform my duties with confidence since I know that people have that belief in my abilities.

The caregivers were therefore, encouraged to learn because they had enough support and motivation which mostly comes from the debriefing sessions.

# 5.7 Learning outcomes and use of information gained

### Main outcomes of learning

The study found that the prevalence of planned learning may be clear enough when we are talking about schooling decisions. This is due to the fact that formalised learning provides objectives of a particular subject together with the learning outcomes that one ought to achieve at the end of the process. On the other hand, informal learning to some extent does not clearly provide objectives and particular outcomes of the process since it can happen unconsciously. When home-based caregivers engage in this learning process they initiate the process without expecting specific results sometimes. For example, the case of Nomasonto who unconsciously learnt how to effectively interact with different clients and she realised months later that such

learning had occurred. Furthermore, most of the caregivers were not aware of the fact that what they know was a result of some learning or practice that they had unconsciously engaged in. Zodwa says that:

I had always thought that some of the things that I was not taught come naturally, I never knew that I had somewhere somehow learnt them unknowingly.

It is important to note that one can engage in informal learning anytime, anywhere, with anyone. Informal learning can be planned in a very thoughtful way or it can be stimulated with no prior intention. Livingstone (2001, p.24) argues that several studies showed that many informal learning activities that result in the accomplishment of new knowledge, understanding or skill begin in an ad hoc, incidental manner and are only consciously recognized after the fact.

When looking at the outcomes of learning and the use of information gained from the process, the discussion is informed by similar studies conducted by Livingston (2001) and Eraut (2004).

Livingstone (2001, p.24) shares the same sentiments with Eraut (2004) when he argues that "if we recognize the general importance of informal learning for the reproduction and development of social life, and if we agree that it is feasible to get past the early reviews to participate in empirical research that may validly identify people's intentional informal learning, there are still other major challenges." I think the first challenge would be identification or recognition of incidental learning initiated by the caregiver since it difficult to realise when the process begins. Secondly, distinction between learning processes and learning outcomes cannot be easily identified.

The current study showed that it is also important to keep in mind that the amount of time that people spend engaging in learning processes may not necessarily be positively associated with successful learning outcomes. For example, a less capable caregiver may have to spend considerably more time to achieve a successful outcome. Hence Livingstone (2001, p.24) argues that much of the research to date on adult learning focuses on documenting the types of learning processes that people are involved in, the amount of time that they engage in these processes and their particular substantive areas of learning. I found that the current and other similar studies

hardly addressed the question of the actual competencies that caregivers have gained from their informal learning activities. This could result from our tendency of the use of informal criteria to determine successful informal learning. It is important to note that no external authority can pose an inclusive set of criteria about either the curriculum that should be learned or satisfactory levels of achievement, let alone ensure inter-subjectively meaningful comparisons between informal learning outcomes (Eraut, 2004, p.20). Hence, the first option here again would be introspection, asking the question of what have caregivers achieved through informal learning activities that they see as important.

The findings of the study supported by literature revealed that much further grounded research is needed to document actual processes of informal learning and training, prevalent thematic emphases and quality of outcomes in order to generate clearer profiles of intentional informal learning. Therefore, it is only then that clear assessments on the impact of informal learning and training on specific skill development such as caregiving can be made. Moreover, it is at this point where conclusion on the effects of informal learning and training on such central social policy areas as workplace productivity, community development and effective citizenship can be drawn.

### Reflection and its importance in learning

The study found that reflection was very important to the caregiver since it was used as a method of teaching and learning. It appeared that since not everyone was able to attend the accredited training sessions organised by CINDI and other government departments, the debriefing session offered an opportunity for those who attended to reflect on their experiences. Though home-based caregivers took the debriefing sessions seriously not of them were fully aware of its importance as a platform for knowledge development through information sharing. For example Gugu confessed that she had not thought of debriefing session as that important but she only attended because it was compulsory and everyone is expected to give a report of how the week unfolded. Gugu says:

I never thought of these sessions to be important primary source of information and had such role in knowledge development until I got to learn from my

colleagues' experiences which informed successful day of my clients' next visit. In one of these sessions I learnt about the importance of support and motivation from colleagues and its impact on my performance when on duty.

Thus people may learn from either their own experiences or from other people's experiences through observation, reflection and dialogue. The study also found that when caregivers engaged in a discussion of a particular topic of interest they had to draw more on their pre-existing knowledge or beliefs in order to come up with conclusion which normally brought clear or renewed understanding of what was being discussed. For example, when caregivers discussed the topic of patience and tolerance they normally make reference to their past experiences where they had to apply one of these "virtues" as they call them. Nompulelo says:

when I visited one of my terminally ill clients I had a challenge as I got to realise that her family did want me to see her anymore while she needed me the most. I then exercised my patience and persisted and demanded to see my client until one of the family members granted me access to see her. This was achieved through my improved communication skills which resulted to practice while on duty.

Thabethe's (2006) study showed that even though the focus was on planned training, the caregivers initiated their own informal learning focusing on specific things that they wanted to know or learn. This process was enabled by the reflection when caregiver interacted about what they had learnt previously with the aim of linking current knowledge with new information. It is through constructive reflection that most caregivers get confidence and motivation to do their jobs since they get support as well as new strategies of overcoming challenges encountered while on duty.

Information sharing/factors encouraging or influencing sharing

Given that most of home-based caregivers' learning occurs informally rather than in a structured method, it is important to note that caregivers are most likely to interact and share their experiences. When people interact they are all in a position to learn or gain new information. Furthermore, in the current study caregivers reported that through peer learning they have a

better understanding of their patients and have grown confidence using the strategies learnt which improved their facilitation skills. Zodwa says:

as young person working with elders I learnt through observation and consultation where possible that being a caregiver doesn't mean I know everything and I know more than my clients. My colleagues taught me that sometimes I should just listen to my clients since they like to feel special and highly appreciate to be treated as normal people.

Therefore, this study showed that the informal learning was very important to the caregivers since most of what they leant on their own contributed the most in their jobs.

The study further showed that information sharing was important to allow for an opportunity for group members to express, discuss and cry over painful memories of loss. It also showed an awareness of the journey of personal growth to date, the dropping of masks, and forming, building and maintaining of new relationships. The study further revealed that interactions between caregivers gave them a platform to draw attention to different styles of dealing with anger and conflict while on duty since families react differently from their services. Nompumelelo states that as a caregiver one needs to have self-control and also have a strong heart so that one can be able to cope with the challenges that come with this kind of profession.

Imagine your client is sharing a sad story and you breakdown in tear instead of consoling your client, it is just not acceptable you know!

Furthermore, caregivers were able to promote awareness of their own prejudices and to resolve to make efforts to change. Thus they got to improve on their communication skills, including listening as well as writing skills.

### Relationship between learning and practice

The study found that there is high correlation between learning and practice since most of what caregivers do while on duty is informed by what they leant. For example, one may have basic counselling skills but if not put into practice they are of no use and a person is running a risk of forgetting the drill. On the other hand if one puts his or her skills into practice they are highly likely to master the drills and there is always room for improvement and learning new skills while practicing what one currently possessed. Furthermore, most of what they know is what they have learnt before and during their time as caregivers, regardless of the mode of learning used. For example, when Silindile was working as a domestic worker she had to learn basic caregiving so that she could provide such service to an elderly lady that she worked for at that time. One must note that she was not taught those caregiving skills (though she provided the service) until she joined Siyasiza where she got basic training and the rest she got while she was already working as a home-based caregiver. Silidile says:

some things are basics that you need not to be taught but just things you learn as you grow such as washing and cooking. The same can be said with basic caring skills of which one can learn by doing and the more you do it the more you learn.

Similarly to the current study, Purdy and Hindenlang's (2005) study showed that all caregivers felt that the experience was helpful and beneficial to them when they had to undertake their duties. The current study showed that caregivers valued and appreciated learning since it assisted them as it provided an opportunity for deeper self-awareness for group members to explore specific aspects of themselves, thus allowing them to reflect on their learning to date. The study also showed that learning helped participants to reflect on their past and see how it relates to the present. Learning is also there to provide members an opportunity to risk deeper self-disclosure.

# 6 Conclusion and summary of findings

The study found that most caregivers had previously administered primary care to one of their own family members. The study showed that the home-based caregivers' experiences with their relatives motivated them to join the organization that catered for the entire community. Besides not being trained as a caregiver most of the caregivers did not finish schools though their literacy competencies varied. However, the study showed that some of the caregivers had strong desires to resume or further their educational studies.

The study revealed that the caregivers did not recognise their informal learning processes but acknowledged benefiting from the process which they were not previously aware of. Furthermore, the study showed the impact of environment in shaping the learning processes of its dwellers through experiences and the nature of opportunities it provided to them. The study also revealed that, since there is not clear a distinction between informal learning process and learning outcome, there was a serious need for formally documenting the criteria or clear indicators of the processes' possible outcomes. Lastly, the study found that reflection and dialogue were crucial aspects of the informal learning processes. Thus, much of the home-based caregivers' informal learning was realised during the debriefing sessions and some their knowledge gained for the process were gathered through their informal conversation with the researcher.

# 7 Summary of the chapter

This chapter analysed and presented the findings using patterns and themes emerging from the stories of caregivers observed and interviewed. It outlined the biographical sketches of women caregivers by focusing on who they are, where they come from, what motivates them, what is their highest level of education, what prior experience they had and what kind of training they have received to prepare them for the caregiving role. The chapter further looked at the methods caregivers used for learning, learning opportunities that they are exposed to, the impact that the environment has had on their learning and factors influencing their learning as well as factors affecting their learning. Lastly, the chapter looked at the caregivers' learning outcomes, with emphasis on the importance of reflection and the relationship between learning and practice.

# **Chapter Six**

#### **Conclusion and recommendations**

### **6.1 Introduction**

In Chapter six concluding remarks and recommendations concerning the study are made. The recommendations made are based on the information presented in Chapter Five. As stated the main objective of this study was to seek a deeper understanding of the informal learning experiences of home-based caregivers from a non-governmental organisation in KwaZulu-Natal.

# **6.2 Summary of the study**

Chapter One provided an introduction to the study by presenting the aim of the study which was to seek a deeper understanding of the informal learning experiences of caregivers from a KwaZulu-Natal based NGO. This chapter further provided a brief history of the context of the study, a rationale for choosing the topic, a statement of the research focus, the broader issues and the conceptual framework of the study together with the research questions and methods of data collection and analysis. Lastly, this chapter discussed the limitations of the study and defined the key terms relevant to the study.

Chapter Two reviewed the literature related to the informal learning experiences of community home-based caregivers supporting families affected by HIV and AIDS. Studies conducted on the impact of HIV and AIDS on South African communities provided a background to the review. Moreover, the chapter looked at how different scholars perceived the notion of caregiver and the role and challenges faced by these caregivers were determined through a review of various relevant studies related or similar to the current one. Having looked at the caregiver' roles and challenges I then looked at how they are trained and which learning methods best suit them. This was achieved by looking at different types of learning and through a brief discussion of adult learning.

Chapter Three discussed two interrelated theories which were used as theoretical lenses when analysing data. Firstly, situated learning is projected by Lave and Wenger (1991) as a model of learning in a community of practice. This type of learning allows an individual (student/learner) to learn by socialization, visualization, and imitation within the context of a community engaged in a particular practice. Lastly, experiential learning is said by Kolb and Kolb (2001) to be an approach to learning in which participants engage in an activity, reflect on the activity critically, and obtain useful insight and learning

Chapter Four described the methodology used in the study by explaining what was done in the study in order to collect data to answer the research questions. I opted to employ a basic qualitative research design to gather data using observation, focus group discussion and in-depth semi-structured interviews as data collection methods. The choice of methods used was dictated by the nature of the problem under study, which required collection of empirical data to describe the informal learning experiences of home-based caregivers from a NGO based in KwaZulu-Natal.

Chapter Five analysed and presented the findings using patterns and themes emerging from the stories of the caregivers who were observed and interviewed. It presented biographical sketches of women caregivers by focusing on who they were, where they came from, what motivated them, their educational backgrounds, what prior experiences they had and what kind of training they had received to prepare them for the caregiving role. The chapter further looked at the methods caregivers used for learning, learning opportunities that they were exposed to, the impact that the environment had on their learning and factors influencing their learning as well as factors affecting their learning. Lastly, the chapter looked at the caregivers' learning outcomes, with an emphasis on the importance of reflection and the relationship between learning and practice.

This concluding chapter revisits the research questions, and provides answers to the research questions. I also reflect on my own learning experiences as a result of the study as well as the challenges faced during the study. Lastly, the chapter presents an overall discussion of the findings.

# **6.3** Revisiting the research questions

The key research question was: what are the informal learning experiences of the home-based caregivers supporting HIV and AIDS-affected families in a KwaZulu-Natal township?

To gain a deeper understanding of the informal learning experiences of home-based caregivers, several sub-questions were used.

- > What informs informal learning experiences of caregivers?
- ➤ How are the informal learning experiences made explicit to inform further learning?
- ➤ What do caregivers do with shared information to inform their practices?

The sub-questions were addressed through a basic qualitative research design which was informed by a theoretical framework comprising situated learning and experiential learning. The thematic data analysis method was used to analyse and interpret the data.

# **6.4** Answers to the research questions

This section gives a brief discussion of the findings and the way they answered the research questions. In order to achieve this, research questions are used as sub headings and brief discussions are then given under each one of them.

### 6.4.1 What informs informal learning experiences of caregivers?

The findings of the study revealed that home-based caregivers were highly likely to experience informal learning processes rather than formal or non-formal learning process. Hence, looking at the biographical sketches of the home-based caregivers, one can conclude that past experiences had a great influence on caregivers' desires to learn. Some of the caregivers stated that the experience of losing some of their family members triggered the desire to learn more about caregiving after having previously provided the service without proper training. Furthermore, the study found that caregivers' educational backgrounds informed their leaning since some engaged in learning with the aim of upgrading their literacy levels. It is also important to note that for some caregivers boredom prompted the will to engage in learning in order to keep the mind

occupied. On the other hand, making up for wasted opportunities was cited as one of the reasons that lead to home-based caregivers' learning processes. The study also found that with some caregivers it was not easy to state their reasons for engaging in informal learning processes since they had not heard of this type of leaning.

## 6.4.2 How are the informal learning experiences made explicit to inform further learning?

It is very important to note that education and training is an on-going process and informal learning never ends. With this in mind, it is very difficult to distinguish or identify the beginning and the end of the learning process. In the unstructured nature of informal learning processes there are no clear pre-existing learning objectives that the learner needs to achieve at the end of the learning process.

Some caregivers stated that once new information is obtained, they then compare it with the related pre-existing knowledge, look out for similarities or differences, and determine the value it adds to the previous experiences. This process usual occurs when caregivers are on duty and it is also realised during the debriefing session. Therefore, the transition totally depends on the outcomes of the learning process and whether further learning is required or not. However, it is important to note that learning is a continuous circle which never ends since knowledge gained often prompts a desire to know more.

### 6.4.3 What do caregivers do with shared information to inform their practices?

Some of the home-based caregivers pointed out that the newly obtained knowledge or skills led to practice or application in solving a particular need. They further added that practice might be the sharing process whereby the caregivers transfer the knowledge among each other and by doing so they also learn more through the feedback given by those whom they dialogue or interact with.

The study showed that the information sharing sessions were of high importance since caregivers were able to share the challenges encountered while on duty. Furthermore, it is the very same debriefing session that allowed caregivers to express themselves and also afforded them the

opportunity to discuss and suggest possible solutions to their challenges. Thus the interactions between caregivers, which also happened outside the debriefing session, brought about new ways of doing things, giving the home-based caregivers various approaches to be employed when on duty. For example, Nomasonto leant from her colleagues during the debriefing session that "patience and tolerance" were key qualities that all caregivers must have in order to provide best service to their clients.

# 6.5 Researcher's reflection of the study

In a basic qualitative research approach researchers are encouraged to voice their own opinions and views within the study. It is vital therefore that I give a brief reflection of how I found the study. In this section I state how I went about doing the study and also outline the challenges encountered.

### The way the study was conducted

The investigative nature of the study dictated that a basic qualitative approach was used. The approach and the population being studied also determined the methods and instruments to be used when collecting data. I spent time observing the home-based caregivers during the family visits and thereafter had a group discussion concerning their learning experiences. Furthermore, I selected half of the group to have a one on one semi-structured interview where I got in depth background and biographic information of each caregiver.

The most interesting part of the study was during the data collection when I visited the HIV and AIDS affected families along with home-based caregivers as a non-participating observer. The informal conversations I had with home-based caregivers were also interesting since some of the caregivers shared their deepest secretes which they never shared with their family members or colleagues. The literature was also the highlight of the study even though there was not much produced locally as most of the studies having been conducted internationally. The following are the most notable points identified when conducting the study:

### Importance of relationships between caregivers and PLWHA

I found that the relationship between the caregivers and their clients (PLWHA) determined how home based caregivers' duty would unfold. Caregivers stated that the reception they got from their clients differed and was mostly informed by the nature of their relationship. Furthermore, some of the families did not take the caregivers jobs kindly making it difficult for caregivers to perform their duties. Positive relationships which were built through trust enabled caregivers to perform their duties effectively. It is important to note that working with people affected by HIV and AIDS meant that caregivers need to maintain a good relationship and assure their clients that whatever discussed during their consultation would be kept between them.

## Challenges encountered during the study

When conducting the study there were challenges that I had to overcome in order to complete the study. One of the challenges that I encountered was the challenge of losing a supervisor in the middle of the research. Working with people affected by HIV and AIDS is sensitive and challenging experience whereby one needs to ensure that proper ethical procedures are followed. Identifying a suitable theoretical framework was a challenge, as a result I opted to employ two inter related theories (situated and experiential learning theories).

### Researchers learning experience

When conducting the study I was exposed to various studies similar to the one being conducted. I encountered various scholars who are experts in the field of adult education such as Jarvis, Livingstone, Wenger, Mezirow and Kolb to mention a few. Furthermore, through the discussions and interviews I leant that information sharing is very crucial in community development since some caregivers were motivated to upgrade their standards (both qualification and conduct) after attending the debriefing session.

During the family visits with the caregivers I found that my presence as a non-participating observer influenced the dynamics of the normal consultation between caregivers and their clients. Caregivers had to introduce me to their clients and briefly outline the objectives of my

presence in order to avoid false hopes of me bringing resources to support the sick. This was also to ensure that they maintain their normal relationship with clients and also ensure that their clients' behaviour was not influenced by my presence.

I also learnt that informal leaning is one of the most effective types of learning for people involved in community work. This natural way of learning, as indicated by Rogers (1997), has characteristics of what is considered most effective informal learning situations: it is situated, contextual, and social. Furthermore, the informal learning processes such as reflection, dialogue and action were identified as significant elements of the informal learning process. This type of learning is experiential since caregivers learn by doing and repetitive practice. Moreover, these experiences are acquired in a certain context or environment hence making the learning process situated.

Informal learning is also one of the cheapest modes of obtaining knowledge and skills. However, there is no clear or proper documentation of this type of learning and the process is not easily identified by those who engage in it. Gereluk, Briton and Spencer (1999), supported by Burns (1999), argue that some adult learning activities have tended to be ignored or devalued by dominant authorities and researchers either because they are more difficult to measure and certify or because they are grounded in experiential knowledge which is more relevant to subordinate social groups. It is therefore vital that in-depth research is conducted to document the actual processes of the informal learning, prevailing thematic emphases and quality of outcomes in order to yield clearer outlines of intentional informal learning. Hence, clear assessments of the impact of informal learning and training on specific skill development such as caregiving can be made after considering the latter.

# Nature and overall role of caregivers in the struggle against HIV and AIDS

The impact of HIV and AIDS on society, families and communities is said by Frohlich (2010, p.374) to be complex. Frohlich (2010) argues that "traditionally, "family" has been the fundamental institution of any society and, ideally, the primary point of provision to its members of care, nurturing and socialization, affording them physical, economic, social, cultural and spiritual security. However, the increasing rate of the growth of the pandemic is dismantling and

jeopardising the growth of families. Furthermore, this leaves many households being headed by young children who are then deprived of their childhood by the pandemic. The situation therefore demands the services of community home-based caregivers to rescue the young and lessen the burden off the family members left behind or give hope to the sick who can still survive thou they are already infected by the pandemic.

When conducting this study I found that there are three major roles that community home-based caregivers play in the lives of their clients. Firstly, they provide health care support and in that way they also reduce the burden of the professional health care sector, start considering that the health sector alone cannot offer long term coping strategies or permanent support system, affected households and communities at large are compelled to provide the support system themselves through primary and community home-based caregiving. Hence, community home-based caregivers mediate between home, clinic and hospitals by providing basic health care.

Secondly, caregivers provide social support to the PLWHA and that assists in reducing the stigma attached to people infected by the pandemic. People infected by HIV and AIDS fear that people will look at them differently and also treat them differently hence they sometimes do not want to mingle with the rest of the community members. Hence, the visits by home-based caregivers are very important and are highly appreciated by the families and the PLWHA.

Lastly, the home-based caregivers provide spiritual support to the people infected by the pandemic and their families. Some of the people infected by the pandemic opt to distance themselves from the community and thereby end up not having someone to talk to. When caregivers visited, people felt that there was still hope in life since they had people who cared about them. Caregivers also encourage their clients to stay positive and try improving their health by carrying out all the necessary precaution as required by the health sector.

### 6.6 Ideas for further research

I believe that there is a greater need for other interested researchers to explore the research further. There is a need to explore the relevance and significance of voluntary service providers such as home-based caregivers within a South African context, also highlighting the

characteristics and qualities of home-based caregivers in our context considering the high rate of unemployment and poverty. Moreover, it will also be of great interest to explore challenges faced by home-based caregivers within their communities and highlight the level of support from other professional health care departments. Interested researchers could also look at the issue of gender when it comes to community home-based care provision, considering that in most studies of this nature participants are women.

I would strongly suggest that for further research, interested researchers should conduct a similar study, but make it a comparative one using a larger sample size from a pool of multiple organizations from various communities. This will yield positive results since we could learn about the informal learning experiences of home-based care givers from other communities of different settings that the one being studied. Owing to time-constraints and research objectives, I was restricted to working with a small size sample; nevertheless, I am confident that a larger sample could have generated more interesting findings. Instead of working with a group of only 12 community home-based caregivers from a single non-governmental organization, further research could explore the experiences of caregivers working in different organizations. The approach to this form of research could also be directed to the beneficiaries of care, that is, PLWHA and their affected families so as to learn first-hand from their experiences.

## **6.7 Conclusion**

The nature of the study afforded me an opportunity to learn from the experiences of community home-based caregivers. The study revealed through home-based caregivers' biographical sketches that there was a great need of the caregiving services in communities especially those in a rural setting. The study also revealed the importance of caregiver education and training considering the fact that most caregivers started providing the service without prior training. Furthermore, most of the caregivers did not finish their high school for various reasons.

The study found that it was difficult to identify incidental learning initiatives and also difficult to distinguish between the learning process and outcome. The study further found that with informal learning, it is not easy to equate the amount of time spent engaging in the process and

successful outcome. Hence, the informal leaning outcomes are different from that of non-formal and formal learning since the latter have structure and the outcomes are predetermined as objectives before the process is undertaken. The study revealed that caregivers learnt something new every day when on duty and that was proven during the debriefing sessions. However, some caregivers admitted that they had leant other things unconsciously since they never noticed the process and its duration. However, they only realised after some time that now they were capable for performing certain tasks. Lastly, the study showed that there was a great correlation between learning and practice since caregivers stated that they performed better after their insightful debriefing session.

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**Appendices** 

Appendix1: Semi-structured observation guide

**Background** 

A basic qualitative study dictates that the researchers become a member or part of the group that

he or she is studying in order get precise data for the study. For the purpose of this study the

researcher will look for patterns of behaviour in a particular community to understand the

assumptions, values and beliefs of participants and make sense of the social dynamics but the

researcher will attempt to remain uninvolved and do not influence the dynamics of the setting.

**Purpose** 

The researcher will make use of observations to get an understanding of the factors or elements

which informs the informal learning experiences of home-based caregivers.

**Observation** 

Reasons or circumstances that lead caregivers to learn

> Ways in which caregivers learn

> The methods used to get information,

> Factors affecting information acquisition

➤ Methods of sharing information

➤ Use of shared information to gain more information

> Factors influencing sharing of information

This is just a guide to give directions; the researcher will note everything that he sees as

important to the study. Some important things might be identified throughout the observation

process hence; the process will not be limited to the above indicators.

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## **Appendix2:** Focus group interview schedule

## **Setting the scene**

(Introduction, purpose of the research, request to write or record responses)

#### Questions

- ➤ How do you define learning as a caregiver?
- ➤ What are your primary and secondary sources for learning?
- ➤ What are the factors influencing you to learn through these (primary and secondary) sources?
- ➤ What do you do with the learning obtained?
- ➤ What role do you play in your own learning process?
- ➤ What is a conducive environment for learning to you?
- > If you share information, what are the factors encouraging you to share?
- ➤ What is reflection?
- ➤ Do you see reflection as important in your learning?
- ➤ What can be done to encourage you from reflection and learning?
- ➤ What are the main outcomes of your learning?
- ➤ Can you see any relationship between your learning and changed practices? Why or Why not?
- What actions do you normally take after learning?
- Are there any things you do to become aware of learning opportunities when working with families?
- ➤ What do you do with the learning opportunities identified?

## **Appendix3: Semi-structured interview schedule**

# **Setting the scene**

(Introduction, purpose of the research, request to write or record responses)

## Questions about the home-based caregivers' profile

(Who they are, where they come from and what they want in life)

#### Questions about the work of the home-based caregivers

➤ Describe your typical day as a home-based caregiver- what are your duties or responsibilities?

(Probe for routine and scope of task)

➤ What inspires you to do this type of a work?

(Probe for motivation)

➤ What do you like doing most/ list?

(Probe for details of chaos

As a caregiver what it the hardest thing you had (have) to do?

(Probe for particular stories to illustrate how strenuous the work is)

What kind of skills and knowledge do you (as a caregiver) need in order to do the work?

(Probe for essential caregivers' skills and knowledge)

➤ What do you do to cope with stress in your work? What kind of support, if any, do you get?

(Probe for individual strengths, networks, means of social and emotional support)

# Questions about home-based caregivers training/learning

Questions to be asked in this section will be drawn or formulated from the data gathered from the focus group discussion.

## **Appendix4:** Letter of consent for the home-based caregivers

William O'Brien residence Ce 1 University of KwaZulu-Natal Pietermaritzburg 3201

P O. Box 10007 Mpophomeni Community Hall Nelson Mandela Highway 3291

#### Re: Letter of consent for the home-based caregivers

#### Dear Participant

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I am a Masters student at the University of KwaZulu-Natal exploring the informal learning experiences of home-based caregivers from a non-governmental organization in KwaZulu-Natal The purpose of this study is to understand the informal learning experiences of home-based caregivers of Siyasiza assisting the Mpophomeni community. This study explores how caregivers learn on their own to improve and empower themselves in order to perform their duties effectively.

If you agree to participate, I assure you that the study is not harmful and there are no known risks involved but it will benefit caregivers by making them aware of the importance of the information they learn intentionally or unintentionally but consciously.

I commit myself to keeping the information you provide confidential. You have the right to withdraw at any point of the study, for any reason, and without any prejudice, and the information you have provided will be turned over to you. There are no known risks from being part of this study and taking part in the research is completely voluntary. I also assure you that your names will not be used during and after the study, if needs be pseudonyms will be used.

I appreciate your participation in this research. If you have any questions about the research study itself, please contact me.

I nank you
Sincerely
Siyanda E. Kheswa
School of Education and Development [Adult Education]
Contact details: email- 204511947@stu.ukzn.ac.za/ getmore@homemail.co.za
Cell: 083 947 5204
Researcher's signature
Caregiver's signature

## **Appendix5:** Letter of consent for the home-based caregivers

William O'Brien residence Ce 1 University of KwaZulu-Natal Pietermaritzburg 3201

Mpophomeni Community Howick 3291

Re: Letter of consent for the home-based caregivers

Dear Participant

I am a Masters student at the University of KwaZulu-Natal exploring the informal learning experiences of home-based caregivers form a non-governmental organization in KwaZulu-Natal The purpose of this study is to understand the informal learning experiences of home-based caregivers of Siyasiza assisting the Mpophomeni community. This study explores how caregivers learn on their own to improve and empower themselves in order to perform their duties effectively.

The researcher will not have a direct contact with families during the data collection process but the permission to observe when they are assisted is necessary. Therefore, families need to agree first before observation takes place.

If you agree to participate, I assure you that the study is not harmful and there are no known risks involved but it will benefit caregivers by making them aware of the importance of the information they learn intentionally or unintentionally but consciously.

I commit myself to keeping the information you provide confidential. You have the right to withdraw at any point of the study, for any reason, and without any prejudice, and the information you have provided will be turned over to you. There are no known risks from being part of this study and taking part in the research is completely voluntary. I also assure you that no names will be used during and after the study, if needs be pseudonyms will be used. Families will be protected against all possible stigmatization or prejudice that they might get because of the status of one of their member.

I appreciate your participation in this research. If you have any questions about the research study itself, please contact me.

study itself, please contact me.
Thank you
Sincerely
Siyanda E. Kheswa
School of Education and Development [Adult Education]
Contact details: email- 204511947@ukzn.ac.za/ getmore@homemail.co.za
Cell: 083 947 5204
Researcher's signature
Family member's signature