CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 Introduction

This mini-dissertation is a report on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province. This research falls under Health Adult Education; one of the four research pillars of the Department of Community and Continuing Education at the University of Limpopo (Turfloop Campus). The theme for the research programme is “from social exclusion to lifelong learning” (Rampedi, 2003).

This opening chapter is intended to give a clear background of the study and would operate as a basis on which to understand the whole mini-dissertation. I will start by explaining the context in which this research emanates from; by outlining the global situation regarding HIV/AIDS and Tuberculosis before narrowing down to South Africa and the Limpopo Province in particular. These are the major influences for the introduction of home based care programmes in Africa. The history and rationale for home based care will also be presented.

The socio-economic situation of Limpopo Province will be highlighted in this chapter. This chapter will also present the aims and objectives of the study. Research questions for the study and delimitation of the study are also presented in this opening chapter. The researcher was motivated to do this study by all the people who are infected and affected by HIV/AIDS; however despite their situation they embark on a sincere process of care and support not only for themselves but also for people in their communities. Phuthanang Home Based Care is one such initiative.

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1 Limpopo Province is a new name for the province previously known as the Northern Province.
1.2 Background of the study

1.2.1 HIV/AIDS and Tuberculosis on a Global Scale

HIV/AIDS has become a global epidemic and remains a global challenge of unprecedented dimensions, and a threat to human development. According to estimates by UNAIDS (2008) on a global scale between 33 and 36 million people were living with HIV at the end of 2007. This shows that the epidemic has stabilised although with unacceptably high levels of new HIV infections and AIDS deaths. Africa is the hardest hit continent, accounting for the large part of the global total. Within Africa the majority of the infected people are in Sub Saharan Africa. According to UNAIDS (2008) Sub Saharan Africa remains the region most heavily affected by HIV, accounting for 67% of all people living with HIV and 75% of AIDS deaths in 2007. Within Sub-Saharan Africa, AIDS has caused the average life expectancy to drop from 62 to 47 years (UNAIDS 2008). In Sub-Saharan Africa the impact of the HIV/AIDS pandemic is excessive and threatens the stability of family units.

Sub Saharan Africa has the highest burden of HIV and AIDS and tuberculosis (TB) in the world. According to Poku (2005) owing to HIV/AIDS on the continent many countries across Africa are now witnessing reduced life expectancies, crumbling and over burdened health systems and fragmented socio-cultural coping networks. According to UNAIDS (2008) tuberculosis remains the most common opportunistic infection for people living with HIV, including those on antiretroviral therapy and a leading cause of death for people living in low income countries. HIV and TB have become co-epidemics in Sub Saharan Africa and in August 2005 the World Health Organisation (WHO) declared the TB epidemic in Africa to be a regional emergency. According to WHO (2005) the annual incidence of TB has risen two to three times in Sub Saharan Africa since 1990 in line with the increase in HIV infections. The high rates of HIV/AIDS and other communicable diseases increases pressure on health resources; and health budgets are getting smaller.

1.2.2 HIV/AIDS and Tuberculosis in South Africa

Statistics South Africa (2007) states that, in Africa South Africa is leading in terms of HIV prevalence rate. They indicate that the HIV prevalence rate in the country is about 17%, these rates
are too high. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 370 000 AIDS related deaths occurring every year according to the United Nations (UNAIDS, 2008). A number of factors have been blamed for the increasing severity of South Africa’s AIDS epidemic, and debate has raged about whether the government’s response has been sufficient.

The legacy of apartheid is strongly felt with the low standards of education, high crime rates, unemployment and wide spread poverty; these issues fuel the rising rates of HIV and AIDS. Using statistics obtained from the South African National HIV Survey (2005) KwaZulu-Natal, Mpumalanga and Free State have the highest HIV prevalence, however other Provinces such as Limpopo also have unacceptably high rates and the impact of HIV cannot be under estimated.

The threat of HIV/AIDS in South Africa is that the disease will probably decrease life expectancy, increase the Infant Mortality Rate, intensify the need of health care, fuel poverty, widen existing inequalities between rich and poor residents, increase the proportion of orphans, and alter the existing age distribution (Swartz and Roux, 2004). HIV/AIDS places a significant burden of care on infected and affected households. This is illustrated by a recent study that found that more than 40% of affected households had reported that a household member had taken time off work or school to care for an AIDS patient. UNAIDS (2004) contends that programmes such as home based care clearly have to be strengthened and expanded in order to support affected households.

1.2.3 History of home based care

World Health Organisation (WHO, 2000) contends that between 70% and 90% of illness care takes place within the home. Research evidence demonstrates that most people would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers (WHO, 2000). Home Based Care (HBC) is one of the best ways for most people to receive quality care.

The first home based care programmes in Africa for people living with HIV and AIDS (PLWA) were first established in Uganda and Zambia in the late 1980s (Williams, 1990). In 1987, nearly 90% of
AIDS patients at Zambia's Chikankata Hospital preferred to be cared for at home than in the hospital. In the light of this, the hospital arranged for teams of health workers to visit their homes once a month, covering an area within a radius of 80km around the hospital. The programme aimed to assess AIDS patients at home for physical, psychological, social and spiritual needs, and to provide for these needs where possible. Counseling and education about AIDS was started within the patients' families and communities (Williams, 1990). A key step was to encourage acceptance of AIDS patients and deal with myths surrounding HIV/AIDS. Home based care draws families to provide care and support to ill people in the home by formal and informal caregivers.

According to Rosenberg, Mabuda, Hartwig, Rooholamini, Oracca-Tetteh and Merson (2005) in Africa most home based care programmes are provided by non-governmental organisations (NGO’s) and faith based organizations (FBO’s) to provide services unavailable in health care institutions. Barnett and Whiteside (2002) state that the encouragement of home based care in the era of HIV/AIDS was intended to reduce economic and human resource pressure which health care systems especially hospitals faced. This is especially so in the hardest hit and poorly resourced countries of Africa. The kind of support provided by home based care programmes varies. Programmes use their own approaches and set their own goals. In some programmes, for example, a home-visiting 'team' consisting of a nurse and a driver will deliver medication and treatment for tuberculosis, abscesses and other AIDS related illnesses. Advice is also given on diet, drugs, hygiene and first aid (Chela and Siankanga, 1991).

Some have 'drop-in' centres for patients living near enough to the hospital to be able to attend. Other teams may place more emphasis on counseling and education. Such teams may employ a social worker or a priest who provides counseling to the family and AIDS education to the whole community. Some programmes train local volunteers so that the burden of caring for AIDS patients may be shared with other families in the community. This also helps overcome the fear that surrounds the disease. This is the case for most community home based care programmes in South Africa.
1.2.4 Rationale for home based care in the HIV/AIDS era

The arguments for home based care are powerful. Hospitals in many countries are simply not coping with the increasing numbers of people in need of their services. Russell and Schneider (2000) argue that in most poor African countries the welfare system is often overstretched and it is common practice for health care facilities to limit services to people living with HIV/AIDS. Most of the burden of care now falls on households and communities; this is also true for South Africa where home based care has become a national priority. In Lesotho, home based care was adopted to avert the ever increasing need for hospitalization of patients with AIDS related diseases. Continuity of care for patients and support for affected families were identified as the pillars of this strategy (Ministry of Health and Social Welfare and World Health Organisation 2002). According to (Akintola, 2004) in most countries in East, Central and Southern Africa, for example, over 50% of hospital beds are currently occupied by people with HIV and AIDS. In Zambia, over half of hospital patients and 70% of hospital patients with tuberculosis are HIV positive and the situation is getting much worse. Zambia expects a 15% annual increase in demand for hospital beds for people living with HIV/AIDS, while the actual number of beds available is expected to remain constant.

While hospital in-patient care is the most expensive way of providing care to people with AIDS, many people with AIDS require acute hospital care for only 10 per cent of the period of their illness. Williams (1990) contends that in Barbados, one study found that over 40% of people hospitalised with HIV or AIDS had no valid medical reason to be in hospital. Therefore, home based care would be the logical alternative. At the same time, funding for health care in developing countries is being cut back by structural adjustment programmes. Home-based care can save hospitals money. In one Zambian study, each home visit costs US$2.00 compared with an average daily costs in hospital of over US$4.00. Many AIDS patients who stay at home derive benefits from being in a familiar and caring environment; they are happier, suffer less from pain and live longer. Having the patient at home may sometimes be easier for caregivers too. Many hospitals, particularly in Africa, do not provide food or other basic support to their patients. They rely on relatives to prepare food, wash and change bedding. It has become an acceptable argument that allowing patients to receive care in a familiar environment improves the experience of dying and death (Akintola, 2008). It has also been
shown to assist in reducing stigma and discrimination as well as facilitate acceptance and disclosure of HIV status (Ncama, 2008).

1.2.5 Home based care in South Africa

According to Russell and Schneider (2000) home based care has become a national policy priority in South Africa as it helps those infected and affected with HIV/AIDS cope better with the pandemic. Most importantly, it makes a significant contribution to relieving the burden of care resulting from HIV/AIDS on the health sector. South Africa in 2001 developed a national home based care strategy which resulted in the introduction of guidelines to operate home based care programmes. According to the Department of Health (DoH, 2001) due to the HIV/AIDS epidemic, the increase in non communicable diseases and the complications thereof, it is necessary to plan how to care for people with disease and their families. The DoH (2001) argues that South Africa has limited health care resources, and situations arise where even if hospital or other institutional care may be the best response to an individual’s condition, it may not be available to him or her.

Akintola (2004) highlighted the need for home based care in view of hospitals commonly discharging patients with HIV/AIDS after a short admission period or not admitting such patients at all due to a lack of resources. Further benefits of home based care programmes are of an economic, social and psychological nature. The main reasons for failure to provide institutional care in South Africa include shortages of hospital beds, inadequate numbers of medical, nursing and allied health professionals in the public sector. These hospitals are often overcrowded and overstretched by the high cost of institutional care. This situation is worse for poor, mostly rural provinces like Limpopo and Eastern Cape. Home based care programmes also has limitations; Akintola (2004) claims that South Africa’s home based care programmes are inadequately developed compared to those in Uganda as they reflect a response of crisis management and entrench gender inequalities. His main criticism is the extent to which home based care programmes in South Africa rely on volunteers (who are usually not paid or paid small stipends for transport) from affected and impoverished communities to carry out basic nursing and care giving activities in patients’ homes. In addition, the extent to which women provide voluntary services as home based caregivers reinforce existing gender stereotypes of women as caregivers. The DoH (2001) anticipated challenges for home based
care initiatives; amongst these challenges are to do with training, insufficient empowerment of caregivers and patients, emotional and physical strain, economic constrains and dependency of the patients. These assumptions have necessitated this study which seeks to investigate challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township.

1.2.6 Adult illiteracy in South Africa

One of the challenges facing South Africa today is the high rate of illiteracy. Of the total South African adult population, 30%, which amount to between six and eight million, is functionally illiterate. Of the 44.8 million of South Africans 4.5 million South Africans had no schooling at all (Statistics South Africa, 2007). There is also a large proportion of the population, which amount to four million that had some primary education however only 1.6 million have completed primary education. The rate of illiteracy in South Africa is high amongst the rural people. In rural areas, illiteracy embedded itself amongst women. Culture played a very crucial role because previously there was a notion amongst Africans that educating a girl child was viewed as a waste of time and money because she will get married and contribute financially in the in-laws’ family. As a result of this, education for girls was not a priority as compared to educating a boy child. Women and girls despite being marginalised in terms of education are at the epicenter when it comes to caring for the sick in home based care programmes.

The country still has a high rate of illiteracy amongst its population especially among women even though Adult Basic Education and Training (ABET) was in place to redress these problems. It is still very difficult for ABET to reach its target of eradicating the mass illiteracy in the country. Limpopo Province has one of the highest numbers of illiterate adults. According to the Department of Education (DoE, 2008) despite the high rates of illiteracy; the province still allocates less than 1% of its provincial education budget on ABET. Home based care and training faces severe challenges as a result of illiteracy; there is therefore need for a paradigm shift in terms of accessibility of education for women so that they can contribute meaningfully to their communities. The relationship between illiteracy and health has been well documented in research; in most cases one feeds on the other becoming a vicious cycle. HIV/AIDS also increases the level of illiteracy amongst the younger generation. In most cases after the death of the parents, children are unable to continue with their
education because they cannot afford to meet the needs of the school let alone the needs of the family; hence they leave the schools early. The situation is much worse for the poor provinces of which Limpopo is one of them; the situation of Limpopo is discussed in the next section.

1.3 The Limpopo Province

1.3.1 Location, History and Population

Figure: 1. Map of Limpopo Province

Source: www.safarinow.com
According to Statistics South Africa (2002) Limpopo Province (previously known as the Northern Province until 2002) constitutes about 13 percent of South Africa’s population. This Province is the fifth largest province in South Africa with a population of more than five million, of which 96% are blacks. Mabasa (2002) states that Limpopo Province is one of the nine new South African provinces that replaced the previous four divisions and ten home lands after the first ‘1994’ democratic elections. Limpopo Province is a result of a merger of three former homelands namely Lebowa, Gazankulu, and Venda after the demise of apartheid in 1994 (Modiba and Zeelen, 2004). This Province is bordered by three African countries namely Botswana, Mozambique and Zimbabwe.

1.3.2 Socio –economic profile of Limpopo Province

About 90 percent of the population lives in rural areas, most of whom fall below the poverty datum line. Limpopo Province is regarded as one of the country’s poor provinces where economic and social development is lower than in other provinces. According to the Department of Education (2008) there are significantly high levels of poverty in Limpopo Province where the incidence of poverty is an unprecedented 18%. In 2006, Limpopo Province had the highest proportion of the poor with 77% of the population living below the poverty income line; Human Sciences Research Council (HSRC, 2006). The province contributes only four percent of the country’s gross domestic product. Informal and personal services are the main employment outlets. Other indicators such as those related to life expectancy, unemployment, literacy, water and energy consumption fall far short of overall national average, especially for black households. According to the Mail and Guardian (2004) Limpopo province records the highest expenditure on social grants almost 90% of its social development budget, this is because about 63% of poverty stricken people rely on child support grants and old age pensions.

According to the Department of Education (2008) Limpopo province is currently the third most illiterate province in South Africa with about 1, 5 million illiterate adults. According to Statistics South Africa about 48% of people living in Limpopo Province are illiterate (www.stassa.gov.za). Illiteracy contributes to social exclusion and poor health; these conditions promote risky sexual behaviour and consequently the spread of HIV/AIDS. Limpopo Province has a poorly developed infrastructure, due to its predominantly agricultural economy.
According to the Mail and Guardian (2004) infrastructural development in the public health sector is unbelievably appalling. Health spending in Limpopo is almost 30% below the national average, it is noted that Limpopo spends only 16% of its budget on health. The Mail and Guardian (2004) contends that in the public sector one doctor must serve a population of about 8500. This is even worse for pharmacists and dentists. The socio–economic situation of Limpopo Province makes it difficult to implement sustainable social development projects.

1.4 Aim of the study

The aim of the study is to investigate the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province.

1.5 Objectives of the study

- The main objective of this study is to identify challenges Phuthanang home based care faces in providing care and training.
- To get insight into the existing skills training programmes offered to caregivers; and by caregivers at Phuthanang Home Based Care.
- To recommend ways of improving the existing training programmes.
- To make recommendations towards addressing problems faced by the organisation in providing care and training.

1.6 Research Questions for the Study

In an attempt to achieve the above aims the following research questions were asked.

Main question:
- What are the challenges faced by Phuthanang Home Based Care in providing care and training?
The following Sub questions were asked derived from the main question above:

- What are the aims and objectives of Phuthanang Home Based Care?
- What are the existing services and training programmes offered by caregivers at Phuthanang Home Based Care?
- What are the experiences of caregivers in relation to training in Home Based Care?
- What is the level of community participation in Phuthanang Home Based Care activities?

1.7 *Significance of the study*

The findings from this study could be significant to various organisations in a many ways. This study could highlight the possibilities of addressing challenges faced by Phuthanang Home Based Care in providing care and training; and can therefore be an eye opener to other home based care and training programmes in resource limited settings, such as informal settlements and rural areas. The Department of Health may also benefit in developing sustainable home based care and training initiatives.

1.8 *Delimitation of the Study*

The study was done in Mankweng Township about 32 kilometers to the east of Polokwane (formerly Pietersburg until 2002) which is the capital of Limpopo Province of South Africa. Mankweng Township constitutes a large area and is mixture of both formal and informal settlements, both urban and rural settlements (www.polokwane.org.za). It accommodates the University of Limpopo (Turfloop Campus), Zion City of Moria and is a long established settlement area. The study has been limited to an organisation providing home based care and training to people living with HIV/AIDS and other terminal illnesses who are out of institutional care. In this research I intend to investigate the challenges faced by Phuthanang home based care in providing care and training in Mankweng Township.
Selecting Phuthanang Home Based Care out of the many home based care initiatives in Polokwane was done not only for pragmatic reasons; that the organisation is close to the University of Limpopo but the poverty that characterise Mankweng area in which Phuthanang Home Based Care is located makes it a unique case to study. Phuthanang Home Based Care apart from providing home based care is also involved in skills training; therefore it is an interesting case to study. This study therefore was more focused on the training component of Phuthanang Home Based Care. The project I selected for research might be an interesting example of the challenges faced by home based care providers who offer training in economically marginalised areas such as rural areas, townships and informal settlements.

1.9 Conclusion

This chapter gave an exposition of the background and general orientation to the study. It has managed to highlight the context in which the study is premised. The researcher managed to clearly outline the HIV/AIDS and TB situation prevailing on a global scale and managed to narrow down to South Africa and Limpopo Province in particular. The socio-economic environment of Limpopo Province has been clearly articulated and it can be summarised as that of poverty and inequality pillars on which HIV/AIDS thrives on. In this chapter the history and rationale for home based care in South Africa has also been explained. One can therefore conclude that home based care is necessary to provide backup for people who cannot be accommodated by the over burdened public health care sector. The next chapter presents the theoretical framework of the study.
CHAPTER TWO: THEORETICAL FRAMEWORK

2.1 Introduction

The previous chapter gave an exposition of the background and general orientation of the study. It covered among other things the history of home based care, the global and local situations of HIV/AIDS, the aim of the study and research questions among others. This chapter will present the debates surrounding major issues in home based care based on literature from researchers in the area of study. The five major models of home based care in South Africa will be discussed. In this section my assumptions on the challenges facing home based care programmes will be discussed, these will be substantiated by literature. Key concepts will also be defined in order to avoid ambiguity in the interpretation of terms. Some of the key concepts include community home based care, training, HIV, AIDS, caregiver and social exclusion.

2.2 Models of home based care

The Concise Oxford Dictionary defines a model “as a representation of a person or a thing or of a proposed structure”. According to Stockburger (1996) models are simplified representations of some aspects of the real world. From these descriptions one can therefore argue that models of home based care can be described as rules, regulations and guidelines adopted in order to guide the implementation, management, monitoring and evaluation of home based care programmes. Different home based care models have been developed and adopted by most countries in an attempt to deal with the HIV/AIDS epidemic.

The success and sustainability of any model is dependent upon, amongst other things, the availability of resources, the level of community participation and the level of ongoing commitment and organisational capacity of the coordinating body (Department of Social Development (DoSD) and the Department of Health (DoH, 2001). The models are not prescriptions therefore in some cases they are merged in line with organisational needs. The Department of Health (DoH) in South Africa adopted the following models (Russell and Schneider, 2000).
2.2.1 Community driven model

The Department of Health (DoH; 2001) notes that the community-driven model is based on integrated service provision through locally-driven initiatives. In all other models, there is a central structure or coordinating organisation. However, whilst this model could be attached to a community structure, this is not necessary. A Community Developer is responsible for liaising with partner organisations and training volunteer caregivers, who then deal directly with patients and their families. Additionally, government departments or NGOs may be approached for resources. Phuthanang home based care seems to fit within this model.

2.2.2 Formal government sector model

This model is led by government departments such as health and welfare, and works in collaboration with various sectoral partners. The home/community-based care programme is coordinated at the district level by a multidisciplinary team of doctors, nurses and a social worker within the hospital structure (Department of Social Development, 2001). A patient is treated at the hospital and where possible, transported home by the hospital. Home visits are conducted by a professional nurse and community health care workers. The patient can go to the clinic for follow-up treatment and be referred back to the hospital if necessary. Other community organisations may assist the family and patient where needed. The advantage of this model is that the formal health and welfare services that coordinate the programme are already well established and receive financial and policy support from government.

2.2.3 Non – governmental organisation/ Community based model

The Non-governmental organisation (NGO) model is located within the community, and is sometimes referred to as the community based model. According to DoH (2001) the entire home-based care programme is initiated by a coordinating NGO. Needs are identified and services are provided by the NGO however, the home care programme can be financially supported by the business and health sectors, social welfare organisations, other non governmental organisations, community based organisations (CBOs) and faith based organisations (FBOs). The home-based care
team may include a professional nurse, social worker, project coordinator and volunteers or community caregivers who are based at the NGO. If the central NGO is well established and is self-maintaining, it can act as an effective coordinator.

2.2.4 Hospice integrated community based care model

According to Department of Health (DoH, 2001) this model sets out to provide the best quality of care for patients and their families. At the core of the model is the person with a terminal illness and that person’s family, as such it reflects a patient centered approach. This core is then supported by the micro community including neighbors, extended family and various agencies including the health sector, community based organisations and hospice that are also focused on caring for the patient and family. This represents a continuum of care and support for the patient. This model represents a shift from relying on professional nurses to community based care givers, from institutionalised settings to home care, a focus on both the patient and family (DoH, 2001).

2.2.5 Integrated home/community based care model centre

The integrated/ community based care model is structured around a care centre, which is located within the community, possibly attached to a church or school, and coordinates home based care services according to the (Department of Health, 2001). The centre is volunteer-run however the Departments of Health and Welfare may send a professional nurse or social worker to offer services at the centre. The centre should offer various services, including pre- and post-test counseling; HIV testing; training of family members and community caregivers as volunteers; distribution of information, education and counseling materials; facilitation of income generating projects; supervision and monitoring of community caregivers; conducting of home visits and patient follow-ups; and referral to and from hospital and other service providers. The centre could also act as a halfway house and provide day care for patients (Uys, 2001).
2.3 Assumptions

The researcher assumes that home based care has challenges of funds, stigmatisation, training and the burden on women. These assumptions are presented in this section with the support of literature.

2.3.1 Lack of funds

According to the World Health Organisation (2002) one of the most serious challenges facing any Home Based Care (HBC) programme is how to fund and sustain the programme over the long term. In some countries, the government is responsible for funding most home based care programmes. In other countries, the primary sources of funding may be international or national donor agencies, NGOs and faith-based organizations. Funding partnerships might also be developed between the government and non-governmental donor agencies. Home based care organisations receive funding and technical support mainly from international non-governmental organisations and development agencies. However, very few donor agencies fund caregiver stipends or salaries (Department of Health, 2004). There is abundant evidence throughout the world of programmes that were evaluated as being successful and necessary but were discontinued. This usually came about because funding either stopped or was inadequate to sustain the programme. The Department of Social Development (2001) notes that every eventuality cannot be considered in budgeting and allocating funds however, checks and balances should be in place; that addresses funding and sustainability from planning through implementation and evaluation.

With the epidemic showing little or no signs of abating, communities are finding it impossible to sustain support. This is due to dwindling material and financial resources in the face of a massive epidemic that affects almost everyone in high-prevalence communities. Despite declining financial and material support, families and communities still provide physical, emotional and moral support. Akintola (2004) notes that community level support comes from volunteers working with home-based care organisations who represent the main source of support for HIV/AIDS affected families. They provide varying degrees of support depending on the level of resources available to them. Care organisations provide patients with medical care and food to affected households. They sometimes support subsistence food production and other income-generating activities.
With respect to state support, funding for home based care should come both from the public health system as part of a continuum of care and from social protection policies. However, policies and implementation vary greatly across countries. In South Africa home-based care organisations are largely initiatives of faith-based organisations, churches, community-based organisations and non-governmental organisations (Akintola, 2004). Although the state funds home based care, the criteria for funding are not clear and only a few care organisations receive financial and material resources.

Another challenge is that the funding mechanisms introduced such as the conditional grant for (Home/Community Based Care) and special allocations (Poverty Relief Programme) were plagued by under-spending problems related to capacity at national and provincial levels. In 2000/2001 none of the funds for Home/Community Based Care were released (Adams and Claassens 2001).

In Botswana the government funds home-based care as a continuation of hospital care but challenges include lack of transport for staff, problems with the referral system and remuneration. However, some governments allow for stipends that cover volunteers’ transport costs. A study of home based care organisations in South Africa showed that about 56% of volunteers received some form of stipend meant to cover basic costs, (Community Agency for Social Enquiry, CASE, 2005). Akintola (2004) on the other hand asserts that home based care programmes in South Africa rely on volunteers (who are usually not paid or paid small stipends for transport) from affected and impoverished communities to carry out basic nursing and care giving activities in patients’ homes.

Most home based care initiatives have problems of limited or no funding and this poses serious operational constrains as the number of people in need of care increases. The costs of care have not been calculated, either on their own or as they contribute to programs. Thus it can be argued that the costs of home care have been greatly underestimated, not least because they do not, as a rule, take account of both direct expenditures (medicines, transportation, labor time) and opportunity costs (e.g., foregone earnings) incurred at the household level as a result of caring for someone living with AIDS. According to Desmond (2000) providing care for a person living with HIV/AIDS imposes considerable costs on the patient, their caregivers and families. The costs to the household include financial resources, time and opportunity costs. The direct costs include, at a minimum, food and
medicine, gloves, bandages, cleaning supplies, water, extra transport costs and labor costs. Households meet these costs in a number of ways, including altering household composition; withdrawing savings or selling assets; reallocating labor; withdrawing children from school; and depending on an extended family system and the community to support and help them.

2.3.2 Stigmatisation

The Oxford Dictionary defines the word “stigmatise” as to describe or consider someone or something as very bad, worthy of extreme disapproval”. Gee and Moran (1988:382) defines stigmatisation as “the acrimonious labeling of individuals or groups who are considered as violating commonly held properties, values or norms”. HIV/AIDS will remain a problem for a longtime, for many people with the disease still live in fear of discovery because of the prevalent stigma and its associated prejudice and discrimination (Parker and Aggleton, 2003). The authors further assert that stigma plays a key role in producing and reproducing relations of power and control. It operates to legitimise the devaluation of some groups and the construction of superiority by others. Stigma is linked to the workings of social inequality. There is therefore a need for proper understanding of issues of stigmatisation and discrimination, in relation to HIV/AIDS. Parker and Aggleton (2003) are of the opinion that the issue requires a broader perception and notion about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings.

In a study in South Africa by Steinberg (2002), only 35 percent of people living with HIV reported having experienced a supportive response from their community, with one in ten recounting hostility and rejection, including outright discrimination. HIV/AIDS stigma is a complex phenomenon that has received an increasing amount of attention and so greater understanding in recent years (Parker and Aggleton, 2002). Stigma, discrimination and social marginalisation are causes of HIV risk and vulnerability and consequences of being HIV positive. According to Jenkins and Sarker (2007) human beings are inherently social animals and their physical and psychological health is damaged when they are isolated and cut off from their social group. The fear of stigma and discrimination also makes people living with HIV/AIDS reluctant to seek care and treatment of their condition.
Research by Summers, Kates and Murphy (2002) has revealed that stigma has a bearing on the willingness of young people to access support services. UNAIDS (2008a) notes that in some cases family members, caregivers and children of people living with HIV/AIDS (PLWA) are also subject to shame and discrimination; in some cases they become targets of violence. South Africa has witnessed a number of violent incidents where young girls or women have been killed, because their HIV status became known. Hikaum (2004:8) posits that around the world, HIV/AIDS related stigma is expressed through ‘social exclusion, personal rejection, direct and indirect discrimination and harassment’, and laws that deprive people living with HIV/AIDS of their rights. It is further asserted that this may include denial of personal dignity and services or rights, such as employment, housing, insurance, education, health care and travel. The association of HIV/AIDS with sex, disease, death and behavior which are considered deviant or taboo is in most cases the cause of such negativity.

HIV/AIDS stigma emanates from the fact that HIV/AIDS is associated with controversial behavior such as prostitution, homosexuality and drug use. The stigma attached to HIV is because of the association of HIV with immorality, promiscuity, dirtiness and sin (Sontag, 1991). As a result of the associated stigma, many people who live with HIV face rejection from the community. According to Chisango (2004) in the high-density urban areas of Zimbabwe, if one is suspected of being HIV-positive, people use street slang, such as ‘Akarohwa nematsotsi’ (describing the infected person as beaten up by thieves). Some of the music on HIV/AIDS exacerbates the stigmatisation of PLWHA, using war language and disaster metaphors (Chisango, 2004).

In a more extreme case a number of people living with HIV/AIDS in South Africa reported that respondents were sometimes locked up or locked out by family members (Russell and Schneider 2000). In their study of family care provision for people living with HIV/AIDS in Uganda, Russell and Schneider (2000) found that family members would sometimes limit or deny care because of stigma. The role stigma plays in shaping the care available to those living with the virus is not new, and stigma has a vital bearing on home and community-based care, seriously challenging assumptions about the caring resource of the family and community.
2.3.3 Training and management skills

The World Health Organisation recommends that home based care includes training of family members, patients and volunteers and community members on the management of common symptoms; provision of support for families to maintain hygiene and nutrition (WHO, 1999). Training of family (primary caregivers) and volunteers is being precipitated by an increasing reliance of governments on lay people as primary caregivers of People living with HIV/AIDS (PLWHA) in community settings, a phenomenon associated with the loss of human capital in the formal health sectors as well as with the sheer volumes of health care needs from high HIV/AIDS morbidity in affected countries (Feeley, Rosin, Fax, Macwangi, and Mazimba, 2004). The World Health Organisation has produced several manuals and guidelines on training and skills of formal and informal caregivers in HBC. The emphasis has been on both skills and knowledge development of caregivers (WHO, 2003). Skills required by caregivers in this context include skills in home nursing, management of HIV/AIDS-related symptoms, care of the terminally ill, TB management, spiritual care, and reporting to and liaison with formal health services. The recent caregiver’s manuals have an added component on skills for supporting antiretroviral treatment in home based care (WHO, 2003).

According to WHO (2002) the Home Based Care team requires adequate education and training. The content of the home based care curriculum should include amongst others:

- Basic information on HIV/AIDS transmission and how to prevent it;
- Basic comfort measures and nursing care for adults and children;
- Managing symptoms and administering medication;
- Use of traditional remedies;
- Universal precautions;
- Palliative care, including counseling terminally ill people, bereavement counseling and pain relief;
- Nutrition; psychosocial support and counseling for ill people, caregivers, orphans
- Managing referrals and resources.
Some education can be provided in combined sessions with all members of the home based care team (including the ill person and family). Such multidisciplinary teaching helps team-building. Separate sessions should be given for education focusing on specific disciplines. Most education can take place in groups; however, members of the home based care team might educate ill people and families in the home (WHO, 2002). The actual training of HIV/AIDS caregivers in home based care has taken different forms in different countries as well as in organisations within countries. A number of training models have been developed to increase numbers of capable caregivers in the communities.

Caregivers need support in the form of education, information, psychosocial support and counseling. Livingstone (2003) also contends that there is a lack of financial and project management skills on the part of home based care Coordinators. Caregivers need education on the basic facts on HIV/AIDS and the ever-changing face of AIDS. They also need education on the various feelings they can expect to go through and how to handle these.

Previous research on community home based care in Botswana has argued that the quality of most care programmes is dependent on their management. In Botswana it is usually elderly caregivers who manage most care giving programmes. Most of the caregivers have a low or no educational background with little relevant skills needed in HIV/AIDS care. According to Kang’ethe (2004) with little or no skill, due to inadequate or no training, most caregivers are not able to ensure good quality care. A further concern highlighted by UNAIDS(2000) is the challenging nature of providing home and community based care for caregivers, specifically in terms of dealing with an incurable and heavily stigmatised condition on an ongoing basis. The burden on caregivers is worsened by the living conditions of caregivers themselves who are frequently unemployed, lacks training and adequate resources such as medication and health care material to provide quality care.

2.3.4 The burden on women

UNAIDS (2008a) states that women across Sub-Saharan Africa are not only more likely to be living with HIV than men, but they are also more likely to be the ones caring for people infected with HIV. According to WHO (2004) globally the AIDS epidemic is affecting girls and women in increasing
numbers. Women are more burdened than men due to HIV/AIDS this has led some scholars to argue that the HIV/AIDS pandemic is gendered. Women and girls are therefore increasingly at risk of becoming HIV positive due to biological vulnerabilities as well as unequal gender relations and other factors (De Bruyn, 1992). Gender-related issues which are known to increase the risks of HIV infection among females in South Africa as they do internationally include the low social status of women and economic dependence on men, (Grieser, 2001). The impact of HIV/AIDS is felt more by women than men.

Traditionally in most patriarchal societies of Africa coincidently these are the countries most ravaged by the AIDS pandemic; women are the “traditional” caregivers. This social role of caring for other family members is even worse as a result of HIV/AIDS. According to UNAIDS (2003) there are a number of studies showing that HIV/AIDS underscores and exacerbates the unequal division of labour within households. This argument was also established by Ogden and Esim (2003) who contend that about 90% of AIDS care takes place in the home and women bear a disproportionate burden of those responsibilities.

WHO (2004) goes on to argue that Southern Africa has the highest number of female headed households approximately 34% of all the households; this is partly as a result of HIV/AIDS compared to 18% in West and Central Africa and 21% in East Africa. A study by Steinberg (2002) has also revealed that in South Africa in three provinces studied almost three quarters of AIDS affected households were female-headed, a significant proportion of whom were battling AIDS related sicknesses. In more than 40% of the female-headed households the main caregiver had taken time off work or school to care for an AIDS patient. Most of the surveyed households were already poor before AIDS appeared, and women and girls paid a price beyond the immediate toil and distress. Their opportunities to advance their education or income generating activities were gradually diminished together with the increase of care duties (Steinberg, 2002). Caregiving by women is usually a continuous process whereby the death of one woman caregiver gives rise to another woman caregiver. According to UNAIDS (2003) much of the burden generated by the death of an adult woman tends to shift to another, usually older woman who steps in to foster orphans.
A further issue that requires consideration is that many women caregivers are themselves living with HIV and yet there may be no one else present in the household to look after them when they fall ill. The role of care would typically fall to another female relative usually the mother (Livingston, 2003). And finally, a woman’s role as care-provider does not end with death of a husband, child, or sibling, as the care of orphans will often fall to grandmothers and aunts who may or may not able or willing to assume this responsibility. HIV/AIDS is now in some countries being referred to as the grandmother’s disease. As mentioned earlier there is an unequal distribution of AIDS caring responsibilities between women and men. Women tend to carry out most of the responsibilities that are more hands-on, laborious, require more time and attention and thereby they incur greater time burdens. On the other hand, responsibilities performed by men, are usually those that have to do with physical strength and finances which can be accomplished in a shorter time. Also while the responsibilities carried out by men are limited to certain activities, those carried out by women cover a wide array of activities, usually the whole range. For instance while men who restrict their caring activities to the provision of financial and material assistance may not always provide such assistance because of absence, desertion, unemployment and other factors, women may have to provide financial support in addition to performing other activities (Akintola, 2008).

### 2.4 Definition of concepts

#### 2.4.1 Home based care (HBC)

According to World Health Organisation (WHO, 2002) home based care (HBC) is the provision of basic nursing care needs by formal and informal caregivers to people in their own homes. This service is available to people who have mental, physical, emotional and social needs. Among people who qualify for this care are those who are living with HIV/AIDS, who are physically frail persons, or those who are terminally ill. The care given is meant to restore and maintain the individual's maximum level of comfort, function and health, including care towards a dignified death. According to WHO (1999) home based care draws on two strengths that exist throughout the world, families and communities. Families are the central focus of care and form the basis of the Home Based Care team. Communities are places where people live and a source of support and care to individuals and families in need.
2.4.2 Training

The term training refers to the acquisition of knowledge, skills and competencies as a result of the teaching of vocational or practical skills and knowledge that relate to specific useful competencies. Sick people, family members, health and community health workers and volunteers all require adequate education and training in prevention, treatment and care. Since many people are illiterate, creative strategies should be developed to provide training.

2.4.3 Human Immunodeficiency Virus (HIV)

According to Gale Encyclopedia of Medicine (2008) HIV refers to a virus that attacks the body's immune system, making the body unable to fight infection. Papalia and Olds (1992) indicate that the virus is transmitted in infected bodily fluids such as semen and blood, as through sexual intercourse, the use of contaminated hypodermic syringes, and placental transfer between mother and fetus. The virus stays in the body for life even if the person may not show any signs of illness.

2.4.4 Acquired Immune Deficiency Syndrome (AIDS)

According to Van Dyke (2005:4) AIDS refers to a collection of opportunistic diseases; infections and some cancers which together or singularly possess the ability to kill an individual in the terminal phase of the illness caused by weakening of the immune system as a result of infection by human immunodeficiency virus (HIV). AIDS is characterized by a decrease in the number of helper T cells, which causes a severe immunodeficiency that leaves the body susceptible to a variety of potentially fatal infections. Although a cure or vaccine is not yet available, a number of antiviral drugs can decrease the viral load and subsequent infections in patients with AIDS. “To say AIDS is a disease is a misnomer; it is a collection of many different conditions that manifest in the human body or specific parts of the body because HIV has impaired the immune system that it can no longer fight the disease causing agents that are constantly attacking it” (Van Dyke, 2005:3).
2.4.5 Caregiver

The word caregiver refers to both the primary caregiver (usually family members) who stays with the patient most of the time and the community caregiver also referred to as a “volunteer” who moves from house to house to help the clients in need of home based care (Kang’ethe, 2004). The researcher recognises the crucial role played by primary caregivers; however in this paper only the community caregivers or “volunteers” belonging to Phuthanang Home Based Care were part of this study.

2.4.6 Social exclusion

According to Power and Wilson (2000) Social exclusion is a multidimensional process of progressive social rapture, detaching groups and individuals from social relations and institutions and preventing them from full participation in the normal, normatively prescribed activities of the society in which they live. Social exclusion relates to the alienation or disenfranchisement of certain people within a society. In most cases social exclusion is a result of systematic discrimination based on race, gender, class, disability or even one’s HIV status. According to Roche (2004) social exclusion deals with barriers to social participation and goes beyond the simplistic notions of poverty being the basis of social exclusion.

2.5 Conclusion

This chapter has managed to highlight the debates surrounding the issues in home based care citing literature from previous researchers in the area of study. The main models of home based care adopted by South Africa to act as guidelines in the implementation of these programmes have been explained. In this section my assumptions on the challenges facing community home based care programmes were discussed. I assumed that community home based care faces challenges of finance, stigmatisation, the burden on women and lack of capacity and management skills. Key concepts were also defined in order to avoid ambiguity in the interpretation of terms. These include community home based care, HIV, AIDS, caregiver and social exclusion. The following chapter will present the methodological considerations for the study, explaining how the study was conducted.
CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter outlines the methodological considerations of the study; that is how the study was conducted. In this section the following aspects shall be presented research design, data collection, data analysis and ethical considerations. As alluded to earlier in the introduction of this report, this study falls within the qualitative paradigm and takes the form of a single case study on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township, Limpopo Province.

3.2 Research design

Merriam (1988) points to traditional research as being based on the assumption that there is a single, objective reality that one can observe, understand and measure. Qualitative research, however, assumes that the world consists of more than one reality and that these realities are highly subject to multiple interpretations (Merriam, 1988). “It is primarily the nature of the enquiry which should decide which methods are most suitable” (Volan, 2003:64). This study seeks to investigate the challenges faced by Phuthanang Home Based Care in providing home based care and training in Mankweng. This study falls within the qualitative research paradigm. According to Cresswell (1994) a qualitative study is an inquiry process of understanding a social and human problem based on building a complex, holistic picture, formed with words, reporting detailed views of informants and conducted in a natural setting.

Denzin and Lincoln (1998:3) argue that, “qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them.” They suggest that this approach is multi-method in focus, making use of several kinds of empirical materials, such as case studies, personal experiences, life stories, interviews, observations, and a variety of different texts. Despite the various methodological streams that characterise qualitative research, Denzin and Lincoln (1998) suggest that these various methods are all interconnected
through a common focus on ‘problematic moments and meanings in individuals’ lives’. The qualitative paradigm has been chosen for it blends well with the nature of my research topic that needs to be explored in detail. For this study the case study design was chosen. A case study is an ideal design for understanding and interpreting educational phenomena. A case study design is employed to gain an in-depth understanding of the situation and meanings for those involved. The interest is in process rather than outcomes, in context rather than a specific variable, in discovery rather than confirmation; insights gained from case studies can directly influence policy, practice and future research (Merriam, 1998:19).

The case study has been chosen for it allows the investigation to retain the holistic and meaningful characteristics of real life events. Denscombe (2003; 31) argues that “one of the strengths of the case study approach is that it allows the researcher to use a variety of sources, a variety of types of data and a variety of research methods as part of the investigation.” In the case study design Cresswell (1994) notes that the researcher becomes an active learner who can tell the story from the participants’ viewpoint.

The single case design was preferred not only for pragmatic reasons which include convenience, limited time and finances to undertake multiple case studies rather it has been considered for the descriptive information gained will be revelatory. According to Yin (1994; 44) “the single case study design is eminently justifiable…..where the case serves a revelatory purpose”. The single-case design was used for it enabled an intensive study of this particular case, on the challenges faced by Phuthanang Home Based Care in providing home based care and training. Single-case designs require careful investigation to avoid misrepresentation and to maximize the investigator's access to the evidence. The case study has also been met with criticism by researchers within social sciences. Yin (1993) raised concerns regarding subjectivity in terms of the research process using the case study design. During this case study process, I made efforts to be aware of my own biases and how these could influence data collection and analysis.
3.3 Data collection

The use of multiple data collection methods is critical in attempting to obtain an in-depth understanding of the phenomena under study. This strategy adds rigor, breadth, and depth to the study and provides corroborative evidence of the data obtained (Denzin & Lincoln, 2000). This is especially critical in case studies. The researcher analysed documents, carried out observations, open ended interviews and facilitated a focus group discussion for collecting data.

3.3.1 Fieldwork

The researcher followed one stream in data collection in order to address a broad range of issues. The stream followed in this research is fieldwork which employed a number of different data collection methods, including open ended interviews, observations, focus group interview and document analyses.

3.3.1.1 Introductory phase

Before embarking on this research I had to seek for a letter of intent from the Head of Department of Community and Continuing Education which I handed over to the Coordinator of Phuthanang Home Based Care. This introductory phase gave me the opportunity to explain the purpose of my study to the Project Coordinator and the Administrator of Phuthanang Home Based Care. I also utilised this time to hand over a copy of my research proposal to the Coordinator of the organisation for future reference. It was also during the initial site visits that I made it clear to the organisation that I was going to carry out scientific research; which means that I would uphold ethical considerations such as confidentiality and informed consent. I assured the interviewees that I would not in any way do anything that would harm them and infringe on their rights.

The preparatory visits were very helpful as they also guided the researcher in the design of data collection techniques. Having created rapport with the subjects in this research I started embarking on extensive fieldwork.
3.3.1.2 Document analysis phase

Written documents available at Phuthanang Home Based Care were accessed during field visits. Some of the documents the researcher intended to review include registers and proposals. One of the advantages of using written documents is that they have a broad coverage of events. I did not manage to get all the documents I had hoped to review such as financial statements and minutes from their meetings this was because the organisation still has to start compiling such statements. However; I managed to access a document highlighting the vision, mission, aims and objectives of the organisation. Yin (1994) notes that documents can be used to corroborate and augment evidence from other sources. The data I obtained from document analyses was used to augment the data I got from fieldwork.

3.3.1.3 Extensive Fieldwork phase

As has been indicated earlier on, I made use of open-ended interviews, which were in-depth in nature. This allowed me to explore the topic of interest more openly, while allowing interviewees to express their opinions and ideas in their own words (Esterberg, 2002). Interviews are an essential source of information in case studies. Yin (1994) notes that open ended interviews enable one to ask respondents for the facts of the matter as well as their opinions.

According to Kvale (1996) at the most basic level, interviews are conversations. Kvale goes on to define interviews as "attempts to understand the world from the interviewee's point of view and to unfold the meaning of peoples' experiences. Open-ended responses to questions provide the evaluator with quotations, which are the main source of raw data. Patton (1987) notes that quotations "reveal the respondents' levels of emotion, the way in which they have organised the world, their thoughts about what is happening, their experiences, and their basic perceptions. I used the interview guide approach which is the most widely used format for qualitative interviewing. In this approach, the interviewer has an outline of topics or issues to be covered, but is free to vary the wording and order of the questions to some extent.
To facilitate correct recording of interviews and reduce the problem of poor recall the interviewer had to record responses on paper with the subjects consent. Another person had to operate as a second recorder and these two records were later compared to ensure uniformity of the responses. All the interviews I conducted with the Project coordinator, the Administrator and eight caregivers were open ended. These are presented in the following sections.

3.3.1.3.1 Stage 1: Project coordinator

Having established the necessary trust through my site visits to Phuthanang Home Based Care I arranged an appointment telephonically with the Project Coordinator for a one on one interview. The interview started at 09h00 the exact time we had agreed upon. Before we could go into any official business for the day I introduced myself formally and briefly highlighted the purpose of the interview, see section A of Appendix B on page 78 of this report. The interview was held at Phuthanang Home Based Care offices in Unit D Mankweng. The interview session with the Project Coordinator was the longest (one hour) for she had a lot of data about the organisation and its activities. As has been indicated earlier on the interview was open ended to allow the respondent to give the facts as well as their opinion on the data required. In order to make sure that all the necessary questions were answered; I made use of an interview guide. For an example of the interview guide I used see Appendix B on page 78 of this report. The Project Coordinator managed to respond to all the questions in the interview guide without difficulty because she has been part of the organisation since its inception in 2003. Having covered all the questions and verified the responses with the Project Coordinator I thanked her for agreeing to be interviewed and ended the interview session.

3.3.1.3.2 Stage 2: Administrator

Having interviewed the Project coordinator; I made an appointment for an interview with the Project Administrator at the same venue for the next day. This gave me enough time to prepare for the next session. I made use of the open ended interview, with the aid of an interview guide for the sake of consistency just as I had done in the previous interview with the Coordinator. We had agreed to have the interview at 09h00; unfortunately we started at 11h00 since the Administrator had to attend to an emergency at the bank. The interview went on well and we managed to cover all the questions in the
interview guide. I had to verify the responses against all the questions because I allowed the respondent to use both English and Northern Sotho so that she could express herself fully.

3.3.1.3.3 Stage 3: Caregivers

I managed to carry out one on one interviews with eight caregivers at Phuthanang Home Based Care. I decided to use random sampling because I felt I needed to give all the caregivers an equal chance of being selected for the study. Because of their number I decided to have two interviews per day for four days. The interviews I conducted with the caregivers were open ended just like those with the Coordinator and Administrator. Open ended interviews have an advantage in that they provide rich responses on the subject under discussion. I allowed the interviewees to respond both in Northern Sotho and English so that they could express themselves more confidently. After each interview session, I verified the interviewees’ responses to make sure I had recorded what they meant. All the interviews went on well and we managed to cover all the questions on the interview guide which is appendix B on page 78 of this report.

3.3.1.3.4 Stage 4: Focus group interview

A focus group is a collective activity where several perspectives on the given topic can be obtained, and where the data is produced by interaction (Gibbs, 1997). In line with the assertion of Krueger (1988) that focus group interviews involve small groups of people with particular characteristics convened for a focused discussion on a particular topic. I conducted one focus group interview with six participants. The following were participants in the focus group interview; The Project Coordinator; Administrator and four caregivers who did not take part in the individual open ended-interviews. Wilkinson (1998) argues that group interviews of various kinds (generically designed focus groups) offer an important opportunity to explore issues relevant to the person in context. This method, according to Wilkinson (1998) provides a valuable methodological tool for social research in general, however they are more useful in case studies. The researcher conducted a focus group interview to capture the challenges faced in providing home based care and training. The focus group interview was held at Phuthanang Home Based Care offices. The researcher utilised the focus group interview in an attempt to answer the main research question:
• What are the challenges faced by Phuthanang Home Based Care in providing care and training?

On the 17th of June 2009, I conducted a focus group interview at the Reconstruction Development Programme (RDP) house used as an office by Phuthanang Home Based Care.

Figure 2: Photograph showing a focus group interview at Phuthanang home based care

There was one group for this discussion, in 45 minutes the group discussed the challenges faced by Phuthanang Home Based Care in providing care and training. The dialogue for the focus group interview was organised around major themes in an attempt to answer the main research question. All the participants were given room to express themselves in the discussion. I assumed the position of a facilitator during the focus group interview, driving the discussion and making sure that all the people present had a chance to speak out their minds without being overshadowed by the extroverts.
3.3.1.4 Observation phase

In this phase I conducted observations at Phuthanang Home Based Care. Field visits to the site of the study gave me an opportunity to make observations of how care and support for people living with HIV/AIDS is rendered at Phuthanang Home Based Care. To strengthen findings overt observations of the setting of the home based care programme were done. Observations were regarded as a supportive and supplementary technique to set into perspective data collected from interviews and the focus group discussion, (Robson 1993:238). Carrying out observations enabled me to come up with a description of a programme as it exists (Rossi and Freeman, 1993). I observed the following:

- Infrastructure
- Facilities
- Equipment
- Space
- Caregivers’ attendance
- Nature of training offered

I used an observation guide see Appendix C on page 83 of this research report so that I could not leave out important issues.
3.4 Data Analysis

After all the phases of data collection had been done; there was a mass of raw data that I had to group and reduce into meaningful workable data. Firstly since the interviews were recorded on paper I had to identify the categories of responses so that coming up with a data matrix would be easier. The research findings are summarised in the data matrix presented as Appendix E on page 86 of this report. Miles and Huberman (1994) note that when you are working with text or less organised displays, you often note recurring patterns and themes, which pull together many pieces of data. The methodology used in this research offered an opportunity to analyse the dynamics of the home based care programme in their holistic nature. The research questions of this dissertation were formulated to investigate a chosen focus in all its complexity in order to understand and derive meaning based on the experiences of the respondents as recommended by (Miles and Huberman, 1994).

Since this study was a single case study, the analysis of data took the form of making a matrix of categories and placing the evidence within such categories. A data matrix interlaces each respondent with each variable to produce a cell containing the appropriate value. An example of the data matrix used in this study is presented in Table 1 on page 35 of this report. According to Kent (2001) the columns in a data matrix are identified with the variables that are being measured and coded one column for each variable. The ultimate goal is to treat evidence as fairly as possible in order to produce compelling analytic conclusions and to rule out alternative interpretations (Yin, 1994). Responses collected from the interviewees were categorised under major themes and a data matrix was used for the analysis. The data from interviews, observations and documents were organised into major themes and categories through content analysis.
Data matrix used in this research based on interviews with the Project Coordinator, Administrator and Caregivers of Phuthanang Home Based Care in Mankweng.

**Table 1: Below shows an example of data matrix used in the study**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Project Coordinator</th>
<th>Administrator</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inception of the project</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Motivation to join the project</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Training programmes and services offered by Phuthanang Home Based Care</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Number of patients on the programme</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Composition of patients in terms of gender</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Patients’ age range</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Identification of new members</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Resistance to join</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Needs of HIV/AIDS infected people</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Is the project meeting these needs?</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Training received by Caregivers</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Training Providers</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Training needs of community members</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Training offered by Caregivers to community members and patients</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Community Participation</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Collaboration</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Community’s views about the Project and Care giving</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>Management Structure</td>
<td>.</td>
<td>.</td>
<td></td>
</tr>
</tbody>
</table>
3.5 Ethical considerations and credibility of the research

In any research study, ethical issues relating to protection of the participants are of vital concern (Marshall and Rossman, 2006). Research on home based care programmes is necessary in order to learn how to improve existing strategies, services and public programmes to help people infected and affected by HIV/AIDS. However it is essential that such research be done in an ethical manner with careful planning and procedures so that the research participants can be protected. Ethical issues abound when research is conducted on participant’s life situations and especially when the research is conducted with HIV/AIDS as the backdrop (Akintola, 2004). Key ethical considerations arising from the research included issues around consent, privacy and sensitivity to real needs and potential problems.

Before embarking on this research I had to seek for a letter of intent from the Head of Department of Community and Continuing Education (Appendix A on page 76 of this report) which I handed over to the Coordinator for Phuthanang home based care. Respondents were assured before, during and after the research process that the information would be kept confidential and that the researcher would not be professionally negligent. The interviewees however agreed to be photographed, and that their photos appear in the research report in order to enrich the findings. Where direct quotes were cited participants were not identified by name. Data gathering was limited to eliciting information that was relevant to the study. The findings from the study were honestly and accurately recorded.

According to Silverman (2001), research is to be judged on whether it produces valid knowledge, and research methods and conclusions must therefore be justified. Miles and Huberman (1994) contend that qualitative research involves the issues relating to objectivity, reliability and validity, as does quantitative research. As pointed out by Silverman (2001), numerous scholars have contributed to what they propose as a synthesis of validity criteria. In order to ensure reliability and validity of the data obtained the Coordinator, Administrator and Caregivers answered more or less the similar questions with slight variations. The two sets of responses confirmed and cross checked each other.
3.6 Conclusion

This chapter managed to highlight the methodological considerations in this research; that is how the study was conducted. In the above sections, I presented and discussed the research design, data collection techniques, and data analysis. This research is purely qualitative took the form of a single case study. The following chapter has the presentation and analysis of findings; based on the research questions. I will present an overview of Phuthanang Home Based Care. The researcher will highlight the aims, objectives, services and training programmes offered by the organisation. This will enable one to identify challenges the organisation faces in an endeavor to offer its services.
CHAPTER FOUR: PRESENTATION AND ANALYSIS OF FINDINGS

4.1 Introduction

The purpose of this study was to investigate the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province. The researcher believed that a better understanding of these phenomena could highlight the possibilities of addressing challenges faced by Phuthanang Home Based Care in providing care and training; and can therefore be a good example to other home based care programmes. This study could also inform other similar projects in resource limited settings such as townships, rural areas and informal settlements.

This chapter presents the key findings obtained from open ended interviews with eight caregivers, the Coordinator of Phuthanang Home Based Care and the Administrator. The findings were also obtained from a focus group interview with four caregivers (not part of the interviewees) and the Coordinator and Administrator. Data was also obtained from observations and document analysis to compliment findings from the main data collection techniques (interviews and focus group interview respectively). This chapter will be organised in terms of the research questions which are recapped as:

Main question:

- What are the challenges faced by Phuthanang Home Based Care in providing care and training?

Sub questions

- What are the aims and objectives of Phuthanang Home Based Care?

- What are the existing services and training programmes offered by caregivers at Phuthanang Home Based Care?
• What are the experiences of caregivers in relation to training for Home Based Care?

• What is the level of community participation in Phuthanang Home Based Care activities?

In this chapter the setting of the study will be presented first to place the study in its context before other findings are presented in more detail. Following is a presentation and discussion of the findings with details that support each finding. The emphasis is on letting the participants speak for themselves (Bloomberg and Volpe, 2008). This is achieved through illustrative quotations taken from interview transcripts where applicable. All the names at the end of these quotations are pseudonyms in order to maintain the research ethic on confidentiality of participants.

4.2 Phuthanang Home Based Care: Overview

Phuthanang home based care was started in 2003 under a marula tree outside Mankweng Hospital with the encouragement from sisters at the Health Clinic dealing with Tuberculosis and HIV/AIDS. Previously there were two groups of volunteers offering home based care in Mankweng which merged to form Phuthanang with 27 people. The two groups of volunteers were operating in an uncoordinated manner, operating without a business plan. The two groups of volunteers were encouraged to merge so that they would be more organised.

The name Phuthanang was derived from a Sotho word “phuthana” which means assist each other. The name Phuthanang home based care basically defines what the organisation seeks to achieve through assisting the sick in the community. Having merged into one big family Phuthanang Home Based Care was registered as a Non Profit Organisation (NPO) and managed to open a bank account using the company name. During the early years the organisation rented one room which they used as an office, as a result they were crammed into that small space.

4.2.1 Aims and objectives of Phuthanang Home Based Care

I reviewed documents about the organisation; this gave me insight into the aims and objectives of Phuthanang Home Based Care. From the available literature and the interviews I held with the
participants it appears that Phuthanang home based care was formed with the following aims and objectives:

- To provide the Mankweng community with information on sexually transmitted infections and HIV/AIDS and other related diseases.
- To offer home based care for people infected and affected by HIV/AIDS.
- To be involved in nutrition and food security training activities.
- To offer skills training to caregivers and community members in order to reduce poverty.
- To help in the prevention of child and women abuse and assist victims.
- To work in collaboration with other organisations that deals with health transformation and education.

From the registers of caregivers at Phuthanang Home Based Care I observed that since the inception of the programme caregivers were exclusively women, this was a cause for concern to the researcher. The organisation has difficulties in proposal writing this was apparent from the few poorly attempted proposals in the files. Lack of adequate funds was also clear after assessing their bank statements.
Figure 3: Below shows Phuthanang home based care office building.

4.3 Findings from Individual interviews, focus group interview and document analysis

4.3.1 Characteristics of Caregivers

4.3.1.1 Age, Gender of Caregivers

Phuthanang Home Based Care has a total of 18 caregivers. Of these two also work as the Project Coordinator and Administrator respectively. The study revealed that the age range of these caregivers is from 28 to 44. In terms of gender all the 18 (100%) of the caregivers are women. This confirms findings by (UNAIDS 2003, Ogden and Esim 2003) who argue that traditionally in most societies of Africa ravaged by the AIDS pandemic women are the “traditional” caregivers. This social role of
caring for other family members is even worse as a result if HIV/AIDS. According to UNAIDS (2003) there are a number of studies showing that HIV/AIDS underscores and exacerbates the unequal division of labour within households.

**Figure 4: Below; shows some of the caregivers at Phuthanang home based care.**

According to Ogden and Esim (2003) about 90% of AIDS care takes place in the home and women bear a disproportionate burden of those responsibilities. Findings from this study confirmed that many caregivers were poor, had no source of income, and therefore were not able to afford what their clients required or demanded. The caregivers in this project are Volunteers who do not receive any stipends for their work. This lack of income discourages men from offering their services to this particular project, and explains why all caregivers are women.
4.3.1.2 Educational levels of Caregivers

Table 2: Educational levels of Caregivers

<table>
<thead>
<tr>
<th>Education levels</th>
<th>Number (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post Matric</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Grade 11-12</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Grade 8 – 10</td>
<td>9</td>
<td>50</td>
</tr>
<tr>
<td>Grade 3-7</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>100</td>
</tr>
</tbody>
</table>

The above Table illustrates that four (22%) of caregivers at Phuthanang Home Based Care have acquired functional literacy. They received education up to grade seven (ABET level 3). However eight (78%) have received education up to grade nine (ABET level 4). This shows that most of these caregivers are literate. Only one caregiver managed to matriculate. None of the caregivers had tertiary education. Caregivers however lack practical skills and this contribute to a low level of care and productivity.

4.3.2 Training experiences of caregivers

In this section I will present the training of caregivers covering the following aspects; type of training received and duration of training sessions.
4.3.2.1 Training of Caregivers

Table 3: Training of Caregivers

<table>
<thead>
<tr>
<th>Description</th>
<th>Number (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers who did not receive any training on care giving</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Caregivers who received some training on care giving</td>
<td>18</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>100</td>
</tr>
</tbody>
</table>

The above table illustrates that all the 18 Caregivers (100%) at Phuthanang Home Based Care received some form of training related to their work. However what is worth establishing is the nature and relevance of the training received.

4.3.2.2 Length of Training received by caregivers

Table 4: Duration of Training

<table>
<thead>
<tr>
<th>Length of Training</th>
<th>Number (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to Two weeks</td>
<td>17</td>
<td>94</td>
</tr>
<tr>
<td>One to two months</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>100</td>
</tr>
</tbody>
</table>

The table above shows that the majority of training (94%) received by caregivers at Phuthanang Home Based Care were in the form of workshops that lasted between one and two weeks. Only one caregiver received training that lasted for two months.
4.3.2.3 Type of Training received by caregivers

Table 5: Showing type of training received by caregivers

<table>
<thead>
<tr>
<th>Type of training</th>
<th>Number</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Counseling &amp; Depression Management</td>
<td>18</td>
<td>100</td>
</tr>
<tr>
<td>Ancillary Home Based Care</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Project &amp; Financial Management</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Human Resource Management &amp; NPO Act</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Voluntary Counseling &amp; Testing</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>HIV/AIDS Management</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Prevention of Mother to Child Transmission &amp; Breastfeeding</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

The above table indicates that all the caregivers at Phuthanang Home Based Care received training on Basic Counseling and Depression Management in form of a Workshop. Only one Caregiver was trained in Ancillary Home Based Care, Voluntary Counseling and Testing (VCT), HIV/AIDS Management and Prevention of Mother to Child Transmission (PMTCT). Of the 18 Caregivers only two were trained in Project and Financial Management. Three caregivers received training in Human Resources and NPO Act. The majority of caregivers indicated that they still need training in many areas.

From the focus group interview there was a consensus on the need for training on how to offer TB training to clients to increase adherence to medicine. There were indications for the need for training programmes on how to handle breastfeeding issues since they have become problematic. Nutrition management is another area of concern by caregiver’s for most indicated that they do not even know food groupings. They argued that eating nourishing food is a precondition for good health, and good food is important especially for the sick. The caregiver’s pointed out that they need to be taught how to write a will so that they can pass on this information to clients who need such assistance to avoid situations where their resources end up in the wrong hands. From the focus group interview it appears
that most caregivers do not know how to use computers cannot write project proposals and have no knowledge about administering TB drugs.

4.3.2.4 Training needs and motivation of caregivers

Caregivers at Phuthanang Home Based Care indicated that they need more of practical skills that they will apply in their day to day work in the provision of care to sick people. This is in line with the principles of adult learning; for adults to learn, the learning experiences must align with his or her developmental tasks and that adults are motivated to learn new material if its applicable to their real life situations (Knowles, Holton & Swanson, 1998). From the findings of this study the caregivers at Phuthanang home based care are intrinsically motivated to participate in home based care more than they are influenced by external factors. They participate in the project as volunteers and do not receive any money for their work.

4.4 Skills Training and services offered by Caregivers at Phuthanang Home Based Care to patients and other community members

Data obtained from interviews and focus group interview revealed that Phuthanang Home Based Care offers a number of services and training programmes related to the provision of home based care in Mankweng Township. Caregivers at Phuthanang Home Based Care are not passive recipients of training; they are also community trainers in their own right. Findings from the interviews and document analysis revealed that Phuthanang Home Based Care helps many patients and community members within the Mankweng area.

According to their patient register there were 85 patients serviced by the organisation at the time of data collection for this research; however these numbers constantly change as people move to and from the Mankweng area. Of the 85 patients 55 are women while 30 are men. The age range of patients in the home based care programme is from four to 75. Although training is available to patients of all ages, it is mostly the middle aged (adults) who usually participate; in line with the principle of adult learning that adults are motivated to learn relevant things which they can apply immediately to improve their life situations (Knowles, Holton & Swanson, 1998).
Table 6: Showing number of patients trained by caregivers at Phuthanang Home Based Care

<table>
<thead>
<tr>
<th>Description</th>
<th>Number (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients trained by caregivers at Phuthanang HBC</td>
<td>37</td>
<td>41</td>
</tr>
<tr>
<td>Patients not yet trained by caregivers at Phuthanang HBC</td>
<td>48</td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>100</td>
</tr>
</tbody>
</table>

From the table above it can be observed that training is a major component of Phuthanang home based care; this is supported by the fact that 41% of the patients they have currently have received some form of training by the caregivers. A big number of the patients who were not trained are either children or bed ridden and too weak to participate.

Table 7: Shows type of training offered to patients by caregivers at Phuthanang Home Based Care

<table>
<thead>
<tr>
<th>Type of training received by clients</th>
<th>Number (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling and psychosocial support</td>
<td>40</td>
<td>47</td>
</tr>
<tr>
<td>Health Education and hygiene</td>
<td>35</td>
<td>41</td>
</tr>
<tr>
<td>Adherence to medication</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>Sewing</td>
<td>75</td>
<td>88</td>
</tr>
<tr>
<td>Baking</td>
<td>79</td>
<td>92</td>
</tr>
<tr>
<td>Growing vegetables</td>
<td>78</td>
<td>91</td>
</tr>
</tbody>
</table>

The table above shows that clients at Phuthanang Home Based Care are more interested in practical training; in areas such as baking, sewing and growing vegetables. This could be because they are likely to benefit financially from such activities. Fewer patients are interested in more theoretical
training in issues related to health education and adherence to medication. Caregivers at Phuthanang Home Based Care train their patients in the following areas:

**4.4.1 Counseling and psycho-social support**

As recommended by the DoH (2001) Phuthanang Home Based Care offers spiritual support to both caregivers and their patients. Before the start of their daily activities the caregivers share some scripture reading, and sing together and pray for strength. Counseling and psycho-social support are offered as a component for palliative care. Findings from this study have shown that all the caregivers have been trained to conduct counseling. In turn they offer informal training on counseling to members of the community.

In most cases the training is done at various churches and sometimes at the community hall in Mankweng. Caregivers offer various types of counseling to community members; these include amongst others HIV/AIDS counseling, marriage and family counseling, substance abuse counseling and grief counseling. From the study it has emerged that all the caregivers are capable of conducting counseling without problems because all of them were professionally trained in the area. Most of the caregivers indicated that because of counseling more people accept their situations and are now free to talk about them than they did before.

**4.4.2 Health education and hygiene**

In order to increase awareness and change attitudes of people regarding their health, Phuthanang Home Based Care has a number of programmes in place to meet this need. They offer community education on basic health issues such as dealing with TB, how to handle patients with opportunistic infections, violence, abuse, the benefits of hygiene and safety in the home among others.
4.4.3 Training in growing nutritious vegetables

The benefits of good nutrition cannot be over emphasized especially people who are living with HIV/AIDS. Phuthanang Home Based Care currently has a small garden where they train community members and their clients how to grow vegetables to improve food security.

Figure 5: Showing vegetable garden at Phuthanang Home Based Care

Caregivers at Phuthanang Home Based Care help their clients in starting home gardens to help improve their nutrition requirements. They also train community members on how to grow vegetables and cook nutritious food. This project though it was well received by community members; is failing to meet its goals because of limited space, seedlings and manure.
4.4.4 Adherence and Compliance monitoring

Caregivers at Phuthanang Home Based Care offer informal training to the community and their home based care clients on the importance of compliance with their medication. In doing this kind of training they work closely with nurses at Mankweng Hospital which is just two kilometers away from their office. The caregivers encourage their patients on Highly Active Antiretroviral Therapy (HAART) and those on Directly Observed Treatment (DOTS) for TB to adhere to their medication. Studies by Abaasa, Todd, Ekoru, Kalyango, Levin, Odeke and Karamagi (2008) at The Aids Support Organisation (TASO) in Uganda have established that poor adherence to highly active antiretroviral therapy (HAART) may result in treatment failure and death. Studies showed that good adherence and improved survival are feasible in community HIV/AIDS programmes such as that of TASO and this can be said for other home based care programmes. The caregivers indicated that they remind their patients to take medication sometimes by sending them messages over the phone if it’s late at night.

4.4.5 Sewing and Baking

In an attempt to improve the capacity of caregivers and also raise money for their sustenance Phuthanang Home Based Care has started a sewing and baking project. In this project caregivers train each other and also their clients from the community how to bake and sew so that the beneficiaries generate some income on their own. However, lack of financial and material resources hampers their progress. Currently the project depends on borrowing a stove and sewing machine they use. This project if it gets the necessary support can be of benefit to the organisation. Their main skills programmes: sewing and baking are offered to mostly to clients who want to improve their lives by starting their small business of sewing.

Apart from training their clients the caregivers conduct home visits where they attend to their clients on the home based care programme. During these visits they are able to identify the problems their clients face and find ways of solving them. Phuthanang Home Based Care also collaborates with a number of departments in carrying out its mandate. They help orphans get registrations such as birth certificates and Identity Documents from the Department of Home Affairs. Those who need education are referred to the Department of Education so that they are given the necessary support.
4.5 Challenges encountered in providing care and training

4.5.1 Lack of Funds

The overwhelming majority of participants indicated that lack of funds was a serious problem affecting the organisation’s effort to provide home based care and training. Research findings indicate that Phuthanang Home Based Care is entirely dependent on the Department of Health for funding. From the focus group interview it was established that the funds allocated to the project are inadequate and do not meet all the needs of the organisation. It was established that the money is used solely for paying rent for the office where the organisation is housed. Data gathered from interviews corroborated findings from the focus group interview that caregivers are interested in
fundraising for the project however they need training on how to fundraise. The Coordinator commented:

“We are so much interested in raising money on our own to avoid solely relying on the Department of Health for funds; if you could teach us how to fundraise we would appreciate”.

The caregivers in unison said:

“There is no one who doesn’t want money; the problem is we do not know how to get it”.

4.5.2 Stigmatisation

From individual interviews and focus group interview most of the caregivers argued that stigmatisation seems to be a problem of the past; however in the beginning of the project people were reluctant to join for fear of being stigmatised. The Mankweng community now considers the home based care programme as a useful component of society and many people are interested in their activities. According to the Project Coordinator it is largely a result of the road shows and door to door visits. These are some comments from some caregivers:

“We do not focus on HIV/AIDS only but address a whole range of community needs as a result the community does not perceive us to be HIV people but rather they see us as partners in development”. (Betty)

“Fear of stigma and discrimination is also preventing people from seeking care support and treatment”. (Anna)
On the other hand the Coordinator said:

“Stigmatisation is still an issue here... some people in our society will not come to us and request for services we offer even if they are in desperate need they go to an extent of dying silently. This is because some of them are our neighbours and church members. They don’t know that we apply confidentiality in our dealings and work with everyone in spite of their status”.

The above excerpts it has been revealed that Phuthanang Home Based Care has to include training of community members to reduce the stigma attached to HIV/AIDS, this will enhance participation in its projects.

4.5.3 Collaboration

Caregivers at Phuthanang Home Based Care highlighted the important role played by collaborations with other organisations. The Department of Home Affairs assists them in registering orphans who need birth certificates and identity documents. The Department of Social Development registers the sick who qualify for disability grants. It appears as though they work closely with the Department of Education, Department of Water Affairs, and Department of Public Works. The organisation also works closely with other community based organisations such as Nobody Home Based Care, Evelyn Lekganyane Home Based Care.

From the findings the organisation seems to be benefiting a great deal from these collaborations. However they face several challenges from these collaborations. The delay in the payment of grants and the provision of food parcels from the Department of Social Development probably becomes a direct challenge to caregiver’s since they are the people who interact daily with the clients. Caregiver’s indicated that some of their patients suffer from stress as a result their sickness becomes worse.
In most cases the patients become so agitated that they end up accusing the caregiver’s of stealing their food parcels and feeding their families on it. The following are some of the responses one of the caregivers on the issue of poor collaboration:

“Food parcels are delivered very late one of my clients has been registered for six months but up to now has not received anything; the last time I visited she said ‘Sister if you do not have my food on your next visit then I know you gave it to your children’”. (Tebogo)

“A patient does not understand. You give him the food you have, she/he refuses, yet you have no money to buy her/him what he/she wants as you are unemployed”. (Lerato)

“Some of our clients have lost hope in receiving their disability grants and even threatens not to let us see them again by locking himself in his house”. (Tebogo)

4.5.4 Burden on women

Findings from this study have confirmed previous findings on the disproportionate burden between men and women in terms of caring for the sick. According to UNAIDS (2003) there are a number of studies showing that HIV/AIDS underscores and exacerbates the unequal division of labour within households. This argument was also established by Ogden and Esim (2003) who contend that about 90% of AIDS care takes place in the home and women bear a disproportionate burden of those responsibilities.

In this study women constitute 100% of the caregivers at Phuthanang Home Based Care. I discovered that the only two men who have a role in the organisation are part of the Board of Directors. On inquiring why there is an absence of men the following comments were made by some of the caregivers:
“Men by their nature are not volunteers; just offer them R500 per month we will not have space here”. (Annah, Betty, Lerato, Mabhudi).

“African men are expected to be the bread winners tell me how can a man go to his wife and say I don’t have money for rent remember I was volunteering”. (Tebogo)

The caregivers interviewed noted that sometimes they have problems dealing with men who are their patients especially those who are bed ridden and need to be bathed. Because the organisation is composed of women only their care can be limited. The following are some comments on the burden on women:

“It is difficult to bed bath a man...both the caregiver and the patient are shy because of our culture”. (Lerato)

“Men end up developing bed sores because they will become aggressive when you want to bath them on the private parts so we just bath them on the upper part of the body”. (Mabhudi)

4.5.5 Sanitary Facilities

Findings from both the Interviews with caregivers and the Focus group interview concur that there is often a lack of sanitary facilities complained that lack and unavailability of care package facilities like napkins, pads, cotton wool, bandages and gloves was a great stressor, especially to those caregivers who had bedridden. The following are three quotations from caregivers to highlight their plight:

“The care package components are not adequate. Sometimes they arrive very late”. (Annah)
“It is difficult for us to assist our clients without gloves; this can lead others to develop bed sore”. (Mabhudi)

“How are we going to protect ourselves if the programme does not have protective facilities like gloves, napkins and many other things?”(Lerato)

4.6 Findings from observations

4.6.1 Infrastructure

Locating Phuthanang Home Based Care is a challenge this is because there is no sign post anywhere on the roads close by as a result one has to rely on information from other people. I observed that only a few people in the Mankweng area know where the organisation is located. On my first field visit I was shocked to realise that some people who stay a few houses from the organisation could not direct me to the office.

Phuthanang Home Based Care makes use of an RDP house in Unit D Mankweng as its office. The house is two roomed and unfenced and has poor security. The sitting room was converted to a reception and doubles up as the boardroom because it is more spacious than the other room. The second room previously a bedroom serves as the main office where important organisational information is kept.

4.6.2 Equipment

There is no proper office furniture available at Phuthanang Home Based Care. The few chairs available are from the caregiver’s homes. I observed that some of the caregiver’s had to sit on the floor while attending meetings. The boardroom has no tables this makes writing difficult for the caregiver’s. In the main office there are no filing cabinets so important organisational information is just piled up in a cardboard box and stuffed in a corner.
Phuthanang Home Based Care does not have a single computer to use for report writing. Neither does it have a photocopier; this makes office work difficult. In order to raise money the organisation has started two projects. The first is a sewing project while the other is for baking. These projects are undermined by shortage of fabrics. Another challenge the projects face is that they rely on borrowing a sewing machine and stove for use in the two projects.

4.6.3 Space

The Reconstruction Development Programme (RDP) house which Phuthanang Home Based Care currently rents is small, and was not designed to house 18 people at the same time. If the organisation gets more volunteers to join the project the problem of accommodation has to be addressed as soon as possible. The organisation has a small garden as a result the vegetables they grow cannot meet their patients’ needs. There is therefore a little space for training in growing of vegetables.
4.6.4 Attendance of Caregivers

Phuthanang home based care operates from 09h00 to 16h30 on working days. However they still carry out home visits to patients on weekends depending on the needs of their patients. For the time I spent on their offices on my field visits caregiver attendance was probably more than 90%. The organisation keeps an up to date attendance register which shows the list of people expected on a daily basis and those who are on leave.

4.6.5 Availability of sanitary facilities

The DoH (2001) recommends that home based care projects should have the following basic medical and assistive devices so that they can operate well:

- Gloves
- Bedpans - re-usable (potty, plastic buckets)
- Catheters, euro bags and colostomy bags
- Plastic; mackintosh and draw sheets
- Cotton wool, gauze and swabs,
- Bandages, plasters and washable cloth
- Disposable pads/incontinence sheets (if affordable) and incontinence underwear
- Soap and washing detergents
- Liquid bleach
- Syringes and needles
- Kleenex and disposable towels Plastic apron
- Supplementary feed and nutritious cultural meals
- Infant feeds

Sanitary facilities necessary in home based care are often a problem at Phuthanang Home Based Care. I established this fact after I requested the Project Coordinator to show me the stock they have of linen savers, gloves and cotton wool. I observed that the available stock was limited considering
the number of patients they service. These findings from observations corroborate what was established earlier through individual interviews and the focus group interview.

4.7 Conclusion

In this chapter the findings of the study were presented and discussed, first by providing the setting of the research. The primary finding of this research is that Phuthanang Home Based Care faces several challenges in its attempts to provide home based care and training in Mankweng. Four major findings emerged from the study; and are summarised as follows: Firstly, Phuthanang Home Based Care is an initiative of women in Mankweng Township most of whom have at least ABET level 3 education; who offer voluntary home based care and training for people infected and affected by HIV/AIDS and other community members. Secondly, Phuthanang Home Based Care offers training to (caregivers and community members) in psycho-social support, nutrition and food security. They also offer Health education, Adherence and Compliance, Basic HIV/AIDS and TB Management and skills in Sewing and Baking. Thirdly Caregivers at Phuthanang are functionally literate; however they require more of practical skills in home based care. Finally, Phuthanang home based care has serious challenges in community participation, collaboration, stigmatisation and shortage of sanitary facilities. The following chapter presents the conclusions; recommendations and reflections of the study based on research questions and the findings presented in this chapter.
CHAPTER FIVE: CONCLUSION; RECOMMENDATIONS AND REFLECTIONS

5.1 Introduction

The conclusion and recommendations that will be presented in this section will be based on the research questions and findings of this study as presented in the previous chapter. This study aimed at investigating the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township. The assumptions of this study were that home based care programmes face challenges of finance, stigmatisation, burden on women and inadequate training of caregivers.

Based on the data I gathered during fieldwork and document analysis, I discovered that there are more challenges Phuthanang Home Based Care faces in its operations. The conclusion and recommendations presented in this chapter could be useful to other organisations offering home based care and training in resource limited settings such as townships, rural areas and informal settlements. This chapter also contains a section on reflections of the research process where I present research experiences from drawing up the research proposal up to writing the final draft of this mini-dissertation.

5.2 Conclusions

The purpose of this case study was to investigate the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township. The conclusions from this study are based on the research questions and findings of this study. Based on the findings of this study one can conclude that though Phuthanang Home Based Care is contributing care and training in Mankweng; it still faces many challenges in its operations.
5.2.1 Characteristics of caregivers

Based on the findings presented in chapter four, one can conclude that caregivers in home based care are predominantly women with little education and training, most of which are not professionally trained in care giving.

5.2.2 Challenges encountered

5.2.2.1 Training

From the findings in the previous chapter it is has been shown that caregivers at Phuthanang Home Based Care have problems in offering quality care as a result of inadequate training of its caregivers. In turn poorly trained caregivers are not effective in delivering training to patients and community members.

It can be concluded that caregivers’ lack of practical skills required to provide effective home based care. There is also a lack of training in Ancillary Home Based Care, HIV/AIDS/Management and Voluntary Counseling and Testing.

5.2.2.2 Funding

The Department of Health is the only source of funding for Phuthanang Home Based Care as a result the organisation has limited finance therefore cannot offer its services adequately. From the findings it can also be concluded that caregivers do not know how to fundraise for their project.

5.2.2.3 Collaboration

From the findings in this research I can conclude that collaboration is crucial in the success of Phuthanang Home Based Care. Currently there is no meaningful collaboration as a result of poor communication that exists between the organisation and its intended partners.
5.2.2.4 Community Participation

This research has emphasised the importance of community participation in home based care. From the findings it seems though the community participates in the Annual General Meetings of the organisation, their participation is limited to selection of Board Members. One can therefore conclude that there is limited community participation in Phuthanang Home Based Care.

5.2.2.5 Stigmatisation

From the findings it can be concluded that stigmatisation is still a challenge in offering care for sick people at Phuthanang Home Based Care. It has been highlighted that still some people are reluctant to offer services as caregivers because of fear of being labeled as HIV positive in the community.

5.2.2.6 Burden on women

Research findings presented in chapter four have revealed that at Phuthanang Home Based Care all the 18 caregivers are women. There are only two men however who are part of the Board of Directors, this also shows that men are only interested in their traditional role of decision making. One can therefore conclude that women are overburdened with caring for the sick.

5.2.2.7 Infrastructure

Phuthanang Home Based Care has poor infrastructure; for they still do not have an office of their own. Rather they rent an RDP house in Unit D of Mankweng Township which is not sufficient for their needs. The building they use as an office is in figure 4 on page 40 of this mini-dissertation is not fenced and gated. There is therefore poor security.

5.2.2.8 Equipment

Phuthanang home based care has no furniture that belongs to it as an organisation. It was established that the chairs and tables the organisation currently uses are borrowed from caregiver’s homes. The
situation is actually pathetic since sometimes caregivers have to sit on the floor. The organisation has no filing cabinets, no computer and no photocopier; essential elements for their operation in record keeping and management. Phuthanang home based care has no equipment rather it depends on the goodwill of some caregivers and members of the community. It can be concluded that without the necessary equipment mentioned above it is difficult to carry out day to day activities.

5.2.2.9 Space

From the findings of this study it has been observed that because of lack of space Phuthanang Home Based Care cannot have a viable vegetable garden. There is no space to accommodate the sewing and baking project. One can conclude that lack of space affects the operations of projects at Phuthanang Home Based Care.

5.2.2.10 Sanitary facilities

From the findings in this study there is a problem of inadequate sanitary facilities at Phuthanang Home Based Care. The organisation does not have the recommended sanitary equipment as stipulated by the Department of health.

5.3 Recommendations

The researcher offers recommendations based on the findings, analysis and conclusions of this study. The recommendations that follow are for:

5.3.1 Training

Based on the conclusions above I recommend that more practical skills for all caregivers and their patients be offered by Phuthanang Home Based Care. Training packages must be developed for caregivers so that they increase their knowledge about how to deliver AIDS care in the most effective ways. Training in treatment literacy should be a compulsory component of Home Based Care training.
I also recommend regular refresher courses incorporating new developments in HIV/AIDS and TB related issues for caregivers. There is also need for training on fundraising, computer skills.

5.3.2 Funding

Since Phuthanang Home Based Care has limited funds I recommend that they establish income generating activities, particularly those that generate resources such as chicken rearing and making herbal remedies. Caregivers can also participate through asking for donations (from companies etc) running a small business (spaza, selling services, selling products, sewing.

5.3.3 Collaboration

There is need to establish, expand and manage strategic partnerships with other sectors in the community in order to enhance the integration of its services. Phuthanang Home Based Care needs to participate more in workshops that deal with home based care so as to meet and exchange ideas with projects doing similar work.

5.3.4 Community participation

I recommend that caregivers at Phuthanang Home Based Care start door to door campaigns and school campaigns in and around Mankweng area informing the community of their existence and the work they do.

5.3.5 Stigmatisation

In any community it is important to include strategies for supporting people living with HIV and AIDS. I recommend that in order to reduce stigma in the community around Phuthanang Home Based Care there is need for information dissemination; factual and accurate information about HIV and AIDS through use of drama, poetry and role plays. Caregivers at Phuthanang Home Based Care must promote social openness about HIV/AIDS in the community as a way to combat HIV-related stigma and discrimination.
5.3.6 Burden on women

Educate men on the need to change their perceptions so that they realise that caregiving is not about women only but that they can also play a meaningful role in the programme. In order to reduce the burden on women organisations such as Phuthanang Home Based Care ought to encourage men to join where possible offering financial incentives for example a stipend of R500 per month for caregivers. This is because men are reluctant to join arguing that they are breadwinners for their families.

5.3.7 Infrastructure

There is a need to have a permanent office for Phuthanang Home Based Care. It is recommended that Phuthanang Home Based Care apply for permanent RDP building that can be renovated to meet its needs. There is a need to put a sign post with Phuthanang home based care logo at the building for easy identification.

5.3.8 Equipment

The absence of equipment affects the running of Phuthanang Home Based Care as a viable organisation. I recommend that they approach other local institutions such as the University of Limpopo which is close by and request for furniture to use in their project. The university can also be requested to donate one computer and a photocopier in that way it will become a partner in development.

5.3.9 Space

For Phuthanang Home Based Care is to operate efficiently there is a need for a permanent building for the organisation so that all its activities are accommodated well.
5.3.10 Sanitary facilities

There is a need for a closer relationship with Mankweng Hospital for the supply of sanitary equipment such as gloves, linen savers, cotton wool and others.

5.4 Recommendations for further study

Based on the limitations of this study that this study was an investigation of the challenges faced by Phuthanang Home Based Care in providing home based care and training; I recommend further studies to be conducted for example on the educational needs of adult caregivers in home based care. Further research can be done by other education researchers for example; an evaluation study about the effectiveness of training programmes offered by home based care organisations in Limpopo Province. The findings from this research though they are an important pointer to the challenges faced by home based care organisations in poor communities; they are in no way exhaustive. With that in mind there is therefore a need for other studies for example comparing challenges in home based care in poor communities with those in the well off settings so that guidelines for success can be developed.

5.5 Reflections

I decided to include reflections of the research process in this research report. Stake (1995:135) contends that qualitative case study is highly personal; and researchers are encouraged to include their personal perspectives. Reflections in my research therefore reveal how I value the research process I undertook. Any research activity is unique from others as a result it presents unique learning points. The research process I undertook presented several learning points that I never anticipated. All the encounters I had during the research process were worthwhile. I learnt and experienced various things from the process of drawing up the research proposal, carrying out field work up to the final write up of this research report.
5.5.1 About the Research proposal

I can safely say my research was smooth sailing because it was based on a solid base that is the research proposal. It took me about seven months to draw up a meaningful research proposal. That process allowed me to do a lot of literature search on the subject I intended to research on. Based on literature; I identified the knowledge gap that exists in relation to home based care programmes in South Africa. I learnt that if one has a clear research proposal; conducting the actual research becomes much easier because one has a map that shows you the directions which one needs to follow.

5.5.2 Research experiences and fieldwork

I enjoyed carrying out research at Phuthanang Home Based Care because all respondents I interacted with were really forthcoming and cooperative. That made my job easier to the extent that carrying out the research was worthwhile. I managed to create rapport and trust with all the members of Phuthanang Home Based Care; from the caregivers to the Project Coordinator; this could have contributed in them being willing to be patient with me in the research process. The fact that I made observations, met and interviewed the respondents over a significant period of time, reviewed documents and conducted a focus group interview provided an opportunity to capture the anticipated outcomes of this study. I am grateful for all that I have learnt from carrying out fieldwork in this research.

5.6 Conclusion

This mini-dissertation is a report of a case study on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province. Chapter five, which is the last chapter of this dissertation, presents the conclusions, recommendations and reflections of the research process.

This research has revealed that though Phuthanang Home Based Care is doing everything in its capacity to provide home based care and training, it faces several challenges and these affect the way
the organisation offers its services. From the research one can conclude that Phuthanang Home Based Care faces challenges of lack of funds, stigmatisation, the burden on women and many other operational constrains presented in this report. However, if the recommendations suggested in this study are incorporated in the operations of the organisation improvements could be realised in the provision of home based care and training.
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INTERNET

www.safarinow.co.za/limpopo province/map
7. APPENDICES

Appendix A

Letter from Head of Department

08 June 2009

The Coordinator: Phuthanang Home Based Care

This letter serves to introduce Mr. Chenjerai Muwaniki (student number 200818349), a Masters student in the Department of Community and Continuing Education at the University of Limpopo (Turfloop Campus). To fulfill the requirements of his course he has to conduct research and he intends to conduct his research at your organization. He wishes to conduct a research project entitled: Challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township, Limpopo Province.

May you grant him access to your organization and offer him the necessary support. At the end of his study he hopes to share the findings of the research with you.

Yours sincerely

Dr Hlulani Mabasa

Head of Department

Community and Continuing Education.
Appendix B:

INTERVIEW GUIDE FOR PROJECT COORDINATOR, ADMINISTRATOR AND CAREGIVERS

SECTION A

My name is Chenjerai Muwaniki. I am a Masters student at the University of Limpopo; in the Department of Community and Continuing Education. I am currently conducting research on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province.

For the purpose of this study, I need information that will enable me to write a report that will be submitted to the relevant stakeholders on the above mentioned title. I am requesting your participation in the project. Your participation will be voluntary. Whatever you say will be kept confidential between you and me.

I will be very happy to share the findings with you after the research.

Thank you

Date________________________

SECTION B

FACTS AND FIGURES

1. When did Phuthanang Home Based Care start?

2. What motivated you to be a Caregiver in this project?

3. What are the aims and objectives of this project?
4. What kinds of services are offered at this project?

5. How many people are you currently having in your project?

6. Of these people how many are male and how many are female?

7. What is their age range?

IDENTIFICATION OF NEW MEMBERS

1. How do you identify people to join this project?

2. Do you sometimes experience resistance by people reluctant to join the project?

3. What are some of the reasons they give?

4. In your view what are the needs of HIV/AIDS infected people who join this project?

5. Do you think the services offered by this project meet the needs of these people?

TRAINING AND MANAGEMENT SKILLS

1. How were you trained/ capacitated to do your daily job in this project?

2. If not trained at all do you think training is important and what kind of training would you require?

3. If trained do you think the training you received was sufficient?

b) Who conducted such training?
4. What was taught during the training?

5. What was the duration of the training?

6. In your view do you think the training was relevant to your needs?

7. Are there any other areas you wish to be trained and what do you think will be the benefits of such training in your work?

8. What training do you offer to your clients and other community members?

9. Do you have the necessary skills to offer such training?

10. Which particular age groups participate in the training?

11. In your view what are the benefits of such training?

COMMUNITY PARTICIPATION

1. Are local people involved in the activities of this project? If yes, how?

2. Do you think Community participation is necessary in your project?

3. At what level is the community involved in the activities of this project?

4. In your view how can community participation be enhanced?

LACK OF COLLABORATION

1. Do you have any collaboration with other NGOs, Government Departments? If yes which ones?
2. What is the purpose of such collaborations?

3. Do you think that your project is benefiting from such collaboration?

LACK OF FUNDING

1. How is this project funded?

2. Do you think the funding the project receives is sufficient? If not how do you generate more funds?

3. Are there any fundraising activities in this project?

a) If yes, what is your role in such activities?

b) If not, what are your views about fundraising for this project?

STIGMATISATION

1. In your view what is the perception of the community about your role in the project?

2. What is the perception of the community about people living with HIV/AIDS?

3. How do these perceptions influence the way you operate in this project?

4. In your view how can these perceptions be changed for the better?

BURDEN ON WOMEN

1. What is the management structure of this organization?
2. How many Caregivers are there in this project?
   a) Of these how many are males and how many are females?
   b) If more females than males, what do you think are the reasons for the under representation of men in the project?

3. What other challenges do women face as the major Caregivers?

4. What do you think needs to be done to increase the number of men in the project?

5. What is the level of education of these Caregivers?
Appendix C: OBSERVATION GUIDE

SECTION A

My name is Chenjerai Muwaniki. I am a Masters student at the University of Limpopo; in the Department of Community and Continuing Education. I am currently conducting research on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province.

For the purpose of this study, I need information that will enable me to write a report that will be submitted to the relevant stakeholders on the above mentioned title. I am requesting your participation in the project. Your participation will be voluntary. I will be conducting observations on how you run your project.

I will be very happy to share the findings with you after the research.

Thank you

Date ________________________________

SECTION B

In this phase I will conduct observations. Field visits to the site if the study would give me the opportunity to make observations of how care and training is offered at Phuthanang Home Based Care. Observational evidence is useful in providing additional information about the topic being studied. Observations enable one to come up with a description of a programme as it exists, Rossi and Freeman (1993). This will give me an insight into the challenges faced by Phuthanang Home Based Care in providing home based care and training in Mankweng.
ASPECTS TO OBSERVE

- Infrastructure
- Facilities
- Space
- Attendance of caregivers
- Nature of training offered
Appendix D: Focus group interview guide

SECTION A

My name is Chenjerai Muwaniki. I am a Masters student at the University of Limpopo; in the Department of Community and Continuing Education. I am currently conducting research on the challenges faced by Phuthanang Home Based Care in providing care and training in Mankweng Township in the Limpopo Province.

For the purpose of this study, I need information that will enable me to write a report that will be submitted to the relevant stakeholders on the above mentioned title. I am requesting your participation in the project. Your participation will be voluntary. Whatever you say will be kept confidential between you and me. Everyone must speak without fear, feel free to contribute.

I will be very happy to share the findings with you after the research.

Thank you

Date ______________________________

SECTION B

The researcher shall utilise the focus group interview in an attempt to answer the main research question:

- What are the challenges faced by Phuthanang Community Home Based Care in providing home based care and training?

There will be one group for this discussion, in 45 minutes the group will discuss the challenges faced by Phuthanang Community Home Based Care. A total of six participants will be invited which are the Coordinator of Phuthanang Home Based Care, the Administrator and four Caregivers in the
programme. Focus group interview has been chosen because they allow respondents to share their thoughts and feelings.
Appendix E

Data Matrix used in this research based on interviews with the Project Coordinator, Administrator and Caregivers of Phuthanang Home Based Care in Mankweng Township.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Project Coordinator</th>
<th>Administrator</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inception of the project</td>
<td>Phuthanang Home Based Care was started in 2003, Under a marula tree outside of Mankweng Hospital. Two groups offering home based care one Itilereng and the other merged to form Phuthanang Home Based Care.</td>
<td>Phuthanang Home Based Care was Formed in 2003, through encouragement from Sisters at Mankweng Hospital.</td>
<td>Phuthanang Home Based Care was formed in 2003.</td>
</tr>
<tr>
<td>Motivation to Join the project</td>
<td>I do not like to see sick people suffering without anyone to help them.</td>
<td>I lost my close relatives to probably AIDS so I want to bring awareness to the community about HIV/AIDS and other STI’s.</td>
<td>There is need to provide care and support to those members of our society who needs it. This is especially so for the sick. Our love for God compels us to help those who are sick.</td>
</tr>
<tr>
<td>Aims and Objectives</td>
<td>To educate people about HIV/AIDS,</td>
<td>To educate people about HIV/AIDS,</td>
<td>To teach the community about</td>
</tr>
</tbody>
</table>
| Services offered | Educate people about HIV/AIDS, STI’s, TB and Nutrition.  
Training patients and community members on how to establish food gardens at their homes.  
Assist the old in compliance when taking medication. | Educate people about HIV/AIDS, STI’s, TB and Nutrition.  
Teach people on how to establish food gardens at their homes.  
Assist the old in compliance when taking medication. | Carry out door to door campaigns on health and safety in the home.  
Bed bathing of bed ridden patients.  
We offer counseling and spiritual support to the sick. |
|----------------|------------------------------------------------------|------------------------------------------------------|------------------------------------------------------|
| STI’S, TB and other contagious diseases.  
To be involved in activities for Orphans,  
To offer home based care to sick people in our community.  
To be involved in training on nutrition and food security activities.  
To help in the prevention of child and women abuse and assist victims.  
To work in collaboration with other organisations that deals with health transformation and education. | STI’S, TB and other contagious diseases.  
To be involved in activities for Orphans,  
To offer home based care to sick people in our community.  
To be involved in training on nutrition and food security activities.  
To help in the prevention of child and women abuse and assist victims.  
To work in collaboration with other organisations that deals with health and education. | HIV/AIDS, TB, STI’s.  
To be involved in activities for Orphans,  
To offer home based care to sick people in our community.  
To be involved in nutrition and food security activities. |
<table>
<thead>
<tr>
<th></th>
<th>Compliance when taking medication.</th>
<th>Do field visits to sick people for purposes of counseling and support. Do door to door campaigns on health and safety.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>Currently we have 85 people on our register but sometimes they figure goes up to 110.</td>
<td>We have many patients joining the project as a result am not sure of the actual number. We are not clear on the actual figures but we serve a big number of people.</td>
</tr>
<tr>
<td>Composition of patients in terms of gender.</td>
<td>30 are males and 55 are females.</td>
<td>30 are males and 55 are females</td>
</tr>
<tr>
<td>Patient’s age range</td>
<td>4 to 60</td>
<td>4 to 60</td>
</tr>
<tr>
<td>Identification of new patients</td>
<td>We do door to door campaigns regularly and identify potential beneficiaries. Some are referred to us by other Home Based Care organisations such as Nobody and Evelyn Lekganyane in Boyne as they move from these places to settle in Mankweng.</td>
<td>We do door to door campaigns regularly and identify potential beneficiaries. Some come by themselves after observing the help we offer others in similar circumstances.</td>
</tr>
<tr>
<td>Resistance to join</td>
<td>We do sometimes experience resistance especially from men. This could be a result of fear of stigmatisation and lack of knowledge.</td>
<td>We sometimes experience resistance to join but in most cases after explaining our mission we get positive responses.</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Needs of HIV/AIDS infected people</td>
<td>Most people who join this project need counseling, food, and money to take care of their families. They also need social support that gives them a reason to continue living.</td>
<td>Most people who join this project need counseling, food, and money to take care of their families. They also need social support that gives them a reason to continue living.</td>
</tr>
<tr>
<td>Is the project meeting these needs?</td>
<td>Yes, we are doing our best to help however there are some problems which are beyond the organisation such as delays in processing disability grants. The late delivery of home based care kits is also a challenge.</td>
<td>Partly, due to challenges such as limited budget we can not meet all the patients’ expectations.</td>
</tr>
<tr>
<td>Training received</td>
<td>Was trained in HIV/AIDS, TB, and Breastfeeding in 2002</td>
<td>Basic Counseling, Depression Management for 2</td>
</tr>
<tr>
<td>by Department of Health in Gauteng. Trained by Department of Health in Voluntary Counseling and Testing (VCT) and Prevention of Mother to Child Transmission (PMTCT) in 2003 in Gauteng. Trained for 3 months for a Certificate in HIV/AIDS Management by an NGO Planned Parenthood Association of South Africa (PPASA) in Gauteng. Received Basic Counseling, Depression Management for 2 weeks by the Department of Health. The workshop was done at Oasis Lodge in Polokwane in 2004. NB: all the training received was for free.</td>
<td>weeks by the Department of Health. The workshop was done at Oasis Lodge in Polokwane in 2004. NB: all the training received was for free.</td>
<td>Depression Management for 2 weeks by the Department of Health. The workshop was done at Oasis Lodge in Polokwane in 2004. NB: all the training received was for free.</td>
</tr>
<tr>
<td>Training Providers</td>
<td>Department of Health, NGO – Planned Parenthood Association of South Africa (PPASA)</td>
<td>Department of Health</td>
</tr>
<tr>
<td>--------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Training Needs</td>
<td>We still require training in the following areas: Computer knowledge, Writing Policies and Project Proposals, Nutrition, Fundraising, Monitoring and Evaluation, Management of TB.</td>
<td>We still require training in Computers, Writing Project Proposals</td>
</tr>
<tr>
<td>Community Participation</td>
<td>The community plays a pivotal role in the operations of this project. We invite the community members to our Annual General Meetings and make consultations on what they expect from our organisation. The election of Board Members for the organisation is done by the community. The community also has need for more input</td>
<td>The community plays a pivotal role in the operations of this project. We invite the community members to our Annual General Meetings and make consultations on what they expect from our organisation. The election of Board Members for the organisation is done by the community. There is need for more input</td>
</tr>
<tr>
<td>Collaboration</td>
<td>Our organisation does not operate alone; we collaborate with various other organisations for various purposes. We work closely with the Department of Health who our source of funds, they also offer training to our people and other material resources necessary in our work. The Department of Home Affairs assists us in registering orphans who need birth certificates and identity documents. The Department of Social Development</td>
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</tr>
<tr>
<td><strong>Funding</strong></td>
<td>From the inception of our project in 2003 the Department of Health has been our only source of funds and without them our organisation will seize to exist. The funds we get can only cover a few operating expenses.</td>
<td>From the inception of our project in 2003 the Department of Health has been our only source of funds and without them our organisation will seize to exist. The funds we get can only cover a few operating expenses.</td>
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<tr>
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</tr>
<tr>
<td>registers the sick who qualify for disability grants. We also work closely with the Department of Education, Department of Water Affairs and Department of Public Works. Our organisation also works closely with other community based organisations such as Nobody Home Based Care, Evelyn Lekganyane Home Based Care. Our organisation is benefiting a great deal from these collaborations.</td>
<td>the sick who qualify for disability grants. We also work closely with the Department of Education, Department of Water Affairs and Department of Public Works. Our organisation also works closely with other community based organisations such as Nobody Home Based Care, Evelyn Lekganyane Home Based Care.</td>
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</tr>
</tbody>
</table>
expenses therefore they are not enough. We have no other way of generating income this is because we are not aware of how to fundraise. We need training on how to carry out fundraising this could reduce our reliance on the Department of Health.

<table>
<thead>
<tr>
<th>Community’s views about the Project and Care giving.</th>
<th>The community has appositive view about Phuthanang Home Based Care. People feel that we are useful members of society. Because of that some people get motivated to join the project especially women. Most men on the other hand are not interested in care giving because we offer our services for free. If there was a salary we could see more men joining.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management Structure</td>
<td>Phuthanang Home Based Care has a Board</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Training offered by caregivers to their patients and community members</th>
<th>Board of Directors that is made up of 8 Members. Of these 5 are Executives namely the Chairperson and Deputy, Secretary and Deputy and The Treasurer. The 3 Non Executive Board Members are the Ward Councilor, Pastor and one Community Member. The office is manned by Two officers who are the Project Coordinator and the Administrator. There are a total of 18 caregiver’s all of whom are women. These women are sometimes overwhelmed by the work.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>We offer training in sewing, baking, growing vegetables, Health education and hygiene, community safety and security.</td>
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<td>We offer training in sewing, baking, growing vegetables, Health education and hygiene, community safety and security.</td>
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